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# Two Studies of Family-Centered Care Family-Centered Care and Shared Decision Making: Are they the same Construct? and The Association of Family-Centered Care and Shared Decision Making with Receipt of all Needed Prescription Drugs and Emergency Department Visits in Children with Asthma

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## DEDICATION

This work is dedicated to Patricia K. Sodomka (1950 – 2010), Patient- and Family-Centered Care visionary, pioneer, leader and advocate, and my mentor and friend. I was fortunate to be able to work with Pat from 2007 until her death in 2010, as a Patient- and Family- Centered Care Intern, at the Medical College of Georgia. From the moment I first met her, I was inspired by her grace, her warmth, her compassion, and most of all her courage and resolve to change the face of healthcare. She will forever be the compass that guides my future endeavors as an advocate, teacher, and researcher of Patient- and Family-Centered Care.

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## ABSTRACT

Family-Centered Care (FCC) is considered the standard of care in pediatrics, being affirmed in 2003 by the American Academy of Pediatrics (AAP). Family centered practices center around five specific provider actions: (1) did the provider spend enough time; (2) did the provider listen carefully; (3) was the provider sensitive to the needs of the family, including their values and customs; (4) did the provider provide information as needed; (5) did the provider make the caregiver feel like a partner in the care of the child. In addition to FCC practices, shared decision making (SDM) has been indicated as important in disease management and is one of the maternal and child health bureaus core outcome measures for children with special health care needs.

Asthma is the most prevalent chronic health condition in children. This is a significant public health burden not only on the children's care givers, but also on schools, employers and the health care system. In many cases asthma cannot be prevented, but improvement of outcomes is an achievable goal. While over the past 2 decades we have seen a substantial increase in therapies available for treating asthma, the prevalence of asthma and the health care use associated with the disease, have not decreased substantially. This suggests we need to look at alternate strategies to manage the disease including those that enable the patient and their families to manage it more effectively. These alternate strategies include family-centered care.

Our study first examined the measures of family-centered care and measures of shared decision making, found in the 2009-2010 National Survey of Children with Special Health Care Needs (NS-CSHCN) to determine if they are separate constructs. Our study found that measures of FCC and SDM are the same construct and should potentially be included together into a more comprehensive measure of FCC.

Our second study then examined specific outcomes relative to the receipt of FCC and the experience of shared decision making in children with asthma. We found that children with asthma who received care that was perceived as FCC or experienced SDM were significantly more likely to receive all of their needed prescription medications and not to have visited the emergency department in the past 12 months.

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# CHAPTER 1

## INTRODUCTION

Asthma is the most common chronic disease among children, affecting over 12%. In the United States, in 2004, it was estimated that the total cost of treating asthma (adults and children) exceeded $16 billion. Hospital care represented over $11 billion of this cost. There have been great advances in the treatment of asthma, especially with pharmacotherapy, but 74% of children with moderate to severe asthma are not receiving adequate treatment (Mattke, Martorell, Sharma, Malveaux, Lurie, 2009). This is a significant public health burden not only on the children's care givers, but also on schools, employers and the health care system. In many cases asthma cannot be prevented, but improvement of outcomes is an achievable goal. There are obvious actions that can lead to improved outcomes, such as prescribing anti-inflammatory medications, writing treatment plans, and standardized therapy in a medical home setting. Less obvious and often complicated actions include addressing such barriers as cultural competence and trust issues between provider and caregiver (Akinbami, Moorman, Garbe, Sondik, 2009).

### Family Centered Care

Family centered care is an approach to health care delivery that is dependent upon an ongoing relationship between patients, their families and the health care providers (Coker, Rodriguez Flores, 2003). The Institute of Patient and Family-Centered Care

(IPFCC) links the definition of Family-Centered Care (FCC), with the value of family in healthcare delivery by acknowledging "that families, however they are defined, are essential to patients' health and well-being and are allies for quality and safety within the health care system (Conway, 2006, pg.5)."

The concept of FCC is not new to health care. This philosophy of care dates back centuries. Dr. Francis W. Peabody, known as an "early super hero of internal medicine" gave an address in the late 1920's to his students concerning what it means to be a physician (Lavisso-Mourey, 2006).

> "Time, sympathy and understanding must be lavishly dispensed, but the reward is to be found in that personal bond which forms the greatest satisfaction of the practice of medicine. One of the essential qualities of the clinician is the interest in humanity for the secret of care of the patient is caring for the patient (Peabody, 1984, pg.818)."

Family-centered care has its roots in pediatric care dating back to the mid-19$^{th}$ century where Florence Nightingale espoused that nursing of children was a "motherly occupation" and affection was openly shared. However, a shift occurred between World War I and World War II where parents simply handed their children over and children's hospitals became dark, sterile, and scary environments. During this time period children were admitted to the hospital alone and parents were only allowed to visit for very short durations, if at all. Studies began to establish after WWII that separation of children from their families has severe detrimental effects on the children and the beginnings of FCC started to take root (Jolly, Shields, 2009). In the ambulatory setting policy change was

driven by children with special health care needs. Today, FCC is considered the standard of care in pediatrics, being affirmed in 2003 by the American Academy of Pediatricians. This includes the ambulatory care setting (AAP, 2003).

While FCC, along with Patient-Centered Care (PCC), have been recognized by multiple bodies as indicated above and also by Healthy People 2020, and most recently by the Patient Protection and Affordable Care Act (PPACA), as integral to health, satisfaction, and quality, a consensus definition has not been achieved, but there is agreement on the principles associated with this care.

> "Information sharing is objective, open, and unbiased. Care is respectful of diversity, cultural and linguistic traditions and care preferences. Medically appropriate decisions that best fit the needs, strengths, values, and abilities of all involved are made together by involved parties, including families at the level they choose. The desired outcomes of medical care plans are flexible and not necessarily absolute. Care is in the context of family and community. (Kuo et al.,2012 pg. 298)."

Implementing FCC in the ambulatory setting revolves around the Medical home concept (Kuo, Bird, Tilford, 2011). This concept specifies that

> "care should be accessible, coordinated, comprehensive, family-centered, culturally effective, continuous, and compassionate. It should be delivered by well-trained physicians who provide primary care and manage and facilitate all care. The physician should be known…and should be able to develop a partnership of mutual responsibility and trust (AAP, 2002, pg. 184)."

However, current evidence that PFCC improves outcomes beyond patient satisfaction is lacking.

**Measuring Family-Centered Care**

There is also not one standard to measure family-centered care and with the addition of attention that the PPACA has given to shared decision making, traditional measures may need expanding. And as healthcare reform continues, funding will depend upon quality care and/or pay for performance, it will become increasingly important to measure the multidimensional aspect of patient- and family-centered care appropriately. Traditional measures typically only measure the interaction between patient/family and provider and leave off important dimensions such as SDM (Hudon, Fortin, Haggerty, Lambert, Poitras, 2011). Including shared decision making as part of the measure of FCC should make for a better, more robust measure to help determine if the practice of FCC is truly being achieved.

**Research Questions**

This study will first attempt to determine if shared decision making is a separate construct from family-centered care, and thus should be measured separately. Alternatively, is SDM part of family centered care and should be included when examining the receipt of such care. This study will then attempt to ascertain whether care that is family centered is associated with improvements in specific outcomes in childhood asthma care. This study will also examine the association of SDM with these same outcomes and compare the results with FCC. This study will utilize the 2009-2010

National Survey of Children with Special Health Care Needs (NS-CSHCN) to answer the following questions:

Study 1 will ascertain through factor analysis if the measures of FCC and the measures of SDM are part of the same construct.

Study 2 will examine the association between perceived receipt of family-centered care and outcomes in healthcare delivery, specifically;

1. Receipt of all needed prescription medications
2. Fewer Emergency Department visits

The NS-CSHCN is a nationally representative sample of children with special health care needs and provides measures of the core components of FCC.

**Conceptual Model**

The theoretical framework for this study was based Donabedian's structure/process/outcomes model for assessing the quality of healthcare, Engel's Biopsyhcosocial Model of health and Andersen's Behavioral Model of Health Services The Donabedian model nor the Biopsychosocial model can fully explain such healthcare utilization. Andersen's (1995) behavioral model of health services utilization provides an additional framework to help explain some outcomes

**Importance of Proposed Research**

This author does not know of any study that has examined the relationship between shared decision making and family-centered care, as found in the 2009-2010 NS-CSHCN. Further, there is a paucity of research studies that have examined the

relationship between FCC and specific health outcomes and no research that examines both FCC and SDM together. There must be additional work to support this positive relationship in order to move forward much needed health care reform efforts. There also needs to be additional work that examines measures of FCC. Also to our knowledge there has not been any study that looked strictly at FCC and its effect on childhood asthma outcomes. As stated earlier, childhood asthma is a significant burden on families and the community and begs for additional means to improve outcomes.

**Limitations**

Limitations include the use of self-reported measures and the use of "on every" rating approach to measure family-centered care. It also does not account for other measures of quality of care such as comprehensiveness of care. Also this data is cross sectional in nature and does not allow for determining causal or temporal relationships. The data is self-reported, including asthmas status and is subject to recall bias. Our study also cannot be generalized to the general pediatric population or the adult population as it only represents the national population of children with special health care needs.

**Summary**

Despite tremendous advancement in childhood asthma treatment, it continues to be a substantial burden on children, families, and the community. There is growing, but limited evidence that family centered care can promote positive outcomes in chronic disease management. This study will contribute to this knowledge base by examining specific outcomes relative to childhood asthma in those receiving family-centered care, as

well as ascertaining the relationship between FCC and SDM, relative to the 2009-2010, NS-CSHCN.

**Organization of the Remainder of the Document**

This dissertation is organized in manuscript format. Chapter 1 provides the introduction. Chapter 2 provides the literature review. Chapter 3 provides the study methods for both manuscripts. Chapter 4 examines the measures of family-centered care and shared decision making. Chapter 5 examines ED visits, and prescription drug use relative to FCC and SDM.

# CHAPTER 2

## LITERATURE REVIEW

### Asthma Overview

Asthma is the most common chronic disease among children, affecting over 12% of children (Mattke, Martorell, Sharma, Malveaus, Lurie, 2009). The Centers of Disease Control reported in 2013 that 14% of children had been diagnosed with asthma in their lifetime and that 9.5% (7.1 million) currently suffer from the disease (CDC, 2013).

Of those with asthma nearly 60% experienced greater than 1 asthma attack in the previous year. Almost 2% of all ambulatory care visits and 2.3% of ED visits (593,000) for children is attributed to asthma. Also in 2006, 5.6% of all hospitalizations for children was related to asthma. This equates to 155,000 hospitalizations or 21 per 10,000 children (Akinbami, Moorman, Garbe, Sondik, 2009). In 2010, asthma accounted for 439,400 hospitalizations and 1.8 million emergency department visits (CDC, 2013).

Asthma limits a child's ability to sleep, play, and learn (Williams, 2006). It is also the most common cause of school absenteeism due to a chronic conditions. Stevens et al (2010) found that nationally, children missed an average of 6.44 days of school per year as compared to their peers without asthma, who missed only 3.41 days per year. This was for a total of 10.5 million days away from school attributed to asthma (CDC, 2013). Additionally only 54.41% of children with asthma participate in organized sports, while 58.75% of children without asthma participate in organized sports (Stevens,

Pickering, Laqui, 2010). Parents lost work productivity related to these absences equal to $719.1 million or $285 per child with asthma (Wang, Zhong, Wheeler, 2005).

In the United States in 2004 it was estimated that the total cost of treating asthma (adults and children) exceeded $16 billion (Akinbami et al, 2009). Hospital care represented over $11 billion of this cost. This number rose to $50.1 billion in 2009 (CDC, 2013). There have been great advances in the treatment of asthma, especially with pharmacotherapy, but care still falls short, with 74% of children with moderate to severe asthma not receiving adequate treatment (Mattke et al, 2009). There has also only been limited decreases in ED visits, down from 19% in 1998 to 16% in 2009. Hospitalizations for asthma showed no decrease for this same time period (Nathan et al, 2012). This is a significant public health burden not only on the children's care givers, but also on schools, employers and the health care system. In many cases asthma cannot be prevented, but improvement of outcomes is an achievable goal. There are obvious actions that can lead to improved outcomes, such as prescribing anti-inflammatory medications, written treatment plans and standardized therapy in a medical home setting. Less obvious and often complicated actions include addressing such barriers as cultural competence and trust issues between provider and caregiver (Akinbami et al, 2009).

> " The paradox of asthma is that, although our understanding of its pathophysiological features and the therapies available for treating the disease have increased significantly over the past 2 decades, the prevalence of asthma, the health care use associated with it, and the disruptions it causes to family and community life have not decreased substantially. These facts suggest a need for

interventions that enable individuals, families…to manage asthma and its consequences effectively (Clark, Mitchell, 2009, pg. S185)."

Successful interventions share some common features, these include; recognition of the multiple factors that influence childhood asthma, tailoring interventions to the individual as much as possible, consideration of the social and physical environments in which the child lives, and involving family members in intervention (Clark et al, 2009).

**Family-Centered Care**

"Children exist in the context of a family and therefore excellent care for the child must include attention to the needs of the family" (Jones, Contro, Koch, 2014, pg.S9). This project will focus on Family-Centered Care specifically, but it is part of the Patient and Family Centered Care revolution. Patient- and Family-Centered Care (PFCC) represents a cultural shift in the delivery of healthcare. The Institute of Medicines' (IOM) in its landmark report Crossing the Quality Chasm- A New Health System for the 21st Century, defines patient-centered care, as "care that is respectful of and responsive to individual patient preferences, needs, and values and ensures that patient values guide all clinical decisions." (IOM, 2001, pg.6). "It is an approach to healthcare practice built on whole-person knowledge, respect for patients' preferences, and fostering a productive clinician-patient relationship (Ferrer, Gill, 2013, pg. 303)." The Institute of Patient and Family Centered Care (IPFCC) takes the definition of patient centered care and links it with the value of family in healthcare delivery.

"It recognizes that the very young; the very old; and those with chronic conditions – the individuals who are most dependent on hospital care and the

broader health care system – are also those who are most dependent on families. Family members are more than surrogates to be called on when the patient is unable to make decision on their behalf; they are essential members of the care continuum and care giving team. It acknowledges the literature that confirms that social isolation is a health risk factor and hospital and ambulatory care policies and practices should not separate patients and families in care giving and decision making (Conway, 2006, pg. 5)."

The AAP says that

"Family-centered care is an approach to health care that shapes health care policies, programs, facility design, and day-to-day interactions among patients, families, physicians, and other health care professionals. Health care professionals who practice family-centered care recognize the vital role that families play in ensuring the health and wellbeing of children and family members of all ages. These practitioners acknowledge that emotional, social, and developmental support are integral components of health care. They respect each child and family's innate strengths and view the health care experience as an opportunity to build on these strengths and support families in their caregiving and decision-making roles. Family-centered approaches lead to better health outcomes and wiser allocation of resources as well as greater patient and family satisfaction"(AAP, 2003, pg. 691).

**The History of Family-Centered Care**

FCC has its roots in pediatric care dating back to the mid-19th century where Florence Nightingale espoused that nursing of children was a "motherly occupation" and affection was openly shared. Sir William Osler, a physician and educator, quoted in 1903, "It is a safe rule to have no teaching without a patient for a text, and the best teaching is that taught by the patient himself (Kuo et al, 2011, pg. 4)." Dr. Francis Peabody wrote as part of an essay that expressed his concern over medical technologies overshadowing the human side of medicine. He wrote, "One of the essential qualities of the clinician is the interest in humanity, for the secret of care of the patient is caring for the patient (Peabody, 1984, pg. 818)." However a shift occurred in medicine in pediatric care, between World War I and World War II where parents simply handed their children over and children's hospitals became dark, sterile, and scary environments. During this time period, children were admitted to the hospital alone and parents were only allowed to visit for very short durations, if at all. Studies began to establish after WWII that separation of children from their families has severe detrimental effects on the children and the beginnings of FCC started to take root (Jolley, Shields, 2009).

Consumers have played a large role in the evolution of FCC. This partly began in maternity care. Family-centered maternity care was first introduced in the 1950's at a time when only 4.5% of the births were attended by a midwife at home and childbirth had become medicalized. During this decade Dr. Dick-Read spoke about causes of pain in child birth and promoted breathing and relaxation techniques as a way to relieve the pain and Dr. John Bowlby was promoting maternal bonding. The La Leche League was founded in 1956 and promoted breast feeding. Additional consumer groups started taking

up the cause in the 1960's (Phillips, 1999). Even with consumer groups driving pediatric and maternity FCC, it was not defined until 1987. It was at this time that Surgeon General Koop launched a national agenda for children with special health care needs. This agenda initiated care that was family-centered, community based, and coordinated as the standard of care for children with special needs (Koop, 1987). Finally in 1992, the Institute for Family-Centered Care (IFCC) was established. It was founded by health professionals and parents who had been leading the charge for change in the 1980s. Their focus (now known as the Institute for Patient-and Family-Centered Care) is to focus on "strengthening family/professional collaborations; changing care in hospitals; improving healthcare facility design; transforming medical education; and advising on health policy (Johnson, 2000, pg. 145)."

More recently, one of the Nation's Healthy People 2010 goals, stated that "families of children with special health care needs will partner in decision making at all levels, and will be satisfied with the services they receive (DHHS, Healthy People 2010)." FCC along with Patient-centered care is a key outcome of Healthy People 2020, for children with special health care needs (DHHS, Healthy People 2020). The 2010 Patient Protection and Affordable Care Act (PPACA) calls for the establishment of a Patient-Centered Outcomes Research Institute and "repeatedly refers to patient-centeredness, satisfaction, experience of care, patient-engagement and shared decision making"(Millenson, Macri, pg.1, 2012; PPACA, 2010).

Today FCC is considered the standard of care in pediatrics, being affirmed in 2003 by the American Academy of Pediatricians. This includes the ambulatory care setting (AAP, 2003). Implementing FCC in pediatric ambulatory care has centered on

the Medical Home Model. This model states that care should be comprehensive, caring, culturally competent, coordinated, continuous and family-centered (AAP, 2002).

**Family-Centered Medical Home**

The American Academy of Pediatrics (AAP) has said that "every child deserves a medical home" and is an essential child health outcome for the 21st century (Sia, Tonnigas, Osterhus, Taba, 2004). The Maternal and Child Health Bureau (MCHB) has identified 6 criteria to determine if a child's care meets the definition of a medical home.

"These criteria are:

- Whether the child has at least one personal doctor or nurse who knows him or her well and a usual source of sick care;
- Whether the child has no problems gaining referrals to specialty care and access to therapies or other services or equipment;
- Whether the family is very satisfied with the level of communication among their child's doctors and other programs;
- Whether the family usually or always gets sufficient help coordinating care when needed and receives effective care coordination;
- Whether the child's doctors usually or always spend enough time with the family, listen carefully to their concerns, are sensitive to their values and customs, provide any information they need, and make the family feel like a partner in their child's care;
- Whether an interpreter is usually or always available when needed (Maternal and Child Health Bureau, n.d.)."

The AAP describes the medical home a model of primary healthcare delivery that is accessible, continues, comprehensive, family-centered, coordinated, compassionate, and culturally effective (Cooley, McAllister, Sherrieb, Kuhlthau, 2009; AAP, 2004). Care received in a medical home should be delivered or supervised by a highly qualified primary care physician, who also will manage and facilitate all needed pediatric care. "The physician should be known to the child and family and should be able to develop a partnership of mutual responsibility and trust with them (AAP, 2004, pg. 1545)." Family centered practices in the medical home centers around 6 specific provider actions: (1) did the provider spend enough time; (2) did the provider listen carefully; (3) was the provider sensitive to the needs of the family, including their values and customs; (4) did the provider provide information as needed; (5) did the provider make the caregiver feel like a partner in the care of the child; and (6) and was a language interpreter provided as needed. These are all part of the tenets of family centered care; information sharing, respect, partnership, and care in context with family needs (Kuo et al, 2011).

Some have suggested that it is particularly important for children with a chronic condition to have a medical home. This is important because having a chronic condition requires collaboration between the family, child and multiple health care providers (Kieckhefer, Greek, Joesch, Kim, Baydar, 2005). Having a medical home that is comprehensive has been shown to increase the ability to participate in afterschool sports activities, decrease number of days missed in school and increased time participating in volunteer activities. Additionally three features of the medical home seem to be very important in decreased morbidity and they are access, comprehensiveness and family-centered care (Stevens, Pickering, Laqui, 2010).

## Measuring Family-Centered Care

As healthcare reform continues and funding will depend upon quality care and/or pay for performance, it will become increasingly important to measure the multidimensional aspect of patient- and family-centered care appropriately (Hudon, Fortin, Haggerty, Lambert, Poitras, 2011). These dimensions should include the whole self or biopsychosocial, the experience of illness, shared decision making/power, and the therapeutic relationship between patient/family and the provider (Epstein, Franks, Fiscella, Shields, Meldrum, Kravitz et al, 2005). Traditional measures typically only measure the interaction between patient/family and provider and leave off important dimensions such as SDM (Hudon, Fortin, Haggerty, Lambert, Poitras, 2011). Measurement of the quality will not just depend upon clinical measures, but also of patients' perceptions of care (Epstein, Laine, Farber, Nelson, Davidoff, 1996).

## Conceptual Framework

The framework for this study is centered on Donabedian's structure/process/outcomes model for assessing the quality of healthcare, Andersen's (1995) Behavioral Health Model, and Engel's Biopsychosocial Model. In Donabedian's framework structure refers to the setting in which care is received and includes such things as organizational structure, culture, and also information technology (Edwardson, 2007). Structure can also include such things as qualifications of care providers, as well as patient characteristics (Elverson, Samra, 2012) Process refers to how and what care is delivered and how it is received and finally outcomes refers to the health status of a person as a result of the care that is received. Outcomes are not only those technical

outcomes like prevention of complications, but also patient satisfaction or a patient's perceived quality of care that is based on interpersonal relationships between the provider and the patient. Donabedian also asserted that structure, process and outcome are not independent but are dependent on one another (Donabedian, 1988). This study will focus primarily on process; family-centered care and its effect on outcomes.

Andersen's Behavioral Health model indicates that use of the health care system is dependent upon multiple factors that are described as predisposing characteristics, enabling resources, and perceived and/or actual need. These factors are influenced by the system of care that is available. The model also accounts for use of healthcare may generate the need for more healthcare i.e. outcomes affect subsequent predisposing factors and perceived need (Andersen, 1995; 2008). Predisposing characteristics are those that suggest the likelihood health care will be needed. These include such things as age, gender, and race/ethnicity (Andersen, 1995). In this current study age, gender and race will be utilized as predisposing characteristics. The literature has demonstrated consistent differences in asthma care utilization between males and females and varies with age. Minority populations continue to be disproportionately affected by asthma as well. Boys are affected more by asthma up until ages 16 to 17 years, when the risk of asthma is similar among the two genders. Black children are affected more than white children, with Asian children having the lowest prevalence (Akinbami et al, 2009). Non-Hispanic black children had lower non-emergency ambulatory care visits, but higher emergency department visits than non-Hispanic white children, even after accounting for the higher prevalence of asthma in black children (Akinbami, Moorman, Garbe, Sondik, 2009). Excess ED visits and hospitalizations may be partially explained by the

availability and quality of ambulatory care (Lieu, Quesenberry, 1997). Studies suggest that socio-economic status does not mitigate this disparity in ED visits and hospitalizations (Law, Oraka, Mannino, 2011).

Enabling resources refer to the ability to access health care resources. These include health insurance status, education level of the parent, and household income (Andersen, 1995). Insurance status is a large predictor of access to health care and those without insurance and/ or low income are more likely to use the ED as their usual source of care. Lack of health insurance has been shown to be a very important barrier to receiving appropriate and timely healthcare (Rose, Garwick, 2003). Studies have shown that children served by Medicaid are particularly at risk for poor asthma outcomes, and have high rates of hospitalization and ER use. This is thought to be due to a combination of factors including genetic predisposition, socioeconomic factors, psychosocial factors, and environmental exposures (Fredrickson, Molgaard, Dismuke, Schukman,Walling 2004) Hospitalization for asthma has been shown to be inversely associated with income. Higher Parental education level, two parent households, a written asthma treatment plan were all associated with fewer ED visits attributable to asthma (Lieu, Quesenberry, 1997). As already stated, single parent households and a mother working outside the home is associated with poorer asthma control. These may be related to competing priorities that lessens parental awareness of their child's daily asthma control and the use of medications (Bloomberg et al., 2009).

Need factors are those factors that require the use of health care services (Andersen, 1995, Andersen, 2008). These need factors include severity or perceived severity of illness. Asthma management requires frequent follow-up and care with a

provider for proper management and if not controlled, acute exacerbations often require ED visits and hospitalizations (Valerio et al, 2006).

The *Biopsychosocial Model* was presented by George Engel as an alternative to the biomedical model in the care of patients or in the practice of medicine. The biomedical model is concerned with the scientific treatment of disease and has little to do with treatment of or care of a patient. The Biopsychosocial model attempts to account for the patient as a whole, where the biomedical model falls short, including the social context in which he lives and his interactions with the health care system or the patient/provider relationship (PPR). (Engel, 1977; 1980).

The patient-provider relationship was described as below by Warfield Theobald Longcope (1877-1953)

> "The relationship between doctor and patient partakes of a peculiar intimacy. It presupposes on the part of the physician not only knowledge of his fellow men, but sympathy. He sits, not as a judge of morals or conduct, but rather as an impersonal repository for confession. The patient, on his part, must feel the need of aid, and few patients come to doctors except with this incentive. This aspect of the practice of medicine has been designed as the art; yet I wonder whether it should not, most properly, be called the Essence (Robert Grahm Center, 2007, pg. 31)"

The essence of family-centered care is taken from the biopsychosocial model and is strongly based on the patient/family/provider relationship.

**Family-Centered Care in the Context of the Patient-Provider Relationship**

The Accreditation Council of Graduate Medical Education (ACGME) recognizes that medical knowledge alone is not sufficient in educating the physicians of the future and sees communication skills as key to patient safety and quality. The council requires these future doctors to demonstrate competency in interpersonal and communication skills (Conway, 2006).

Communication within a patient/provider relationship (PPR) can lead to better physical health through an improved ability to diagnose disease and determine a proper treatment with in the context of the individual. Psychosocial health can be improved through the PPR when patients feel validated, worthy and supported. Further the PPR can affect positive outcomes in medicine through satisfaction with care, trust in provider, leading to motivation to adhere to treatment plans, ultimately leading to improved outcomes (Street, Makoul, Arora, Epstein, 2009). Some studies suggest that certain behaviors on the part of the physician will improve outcomes. For example, Clark et al, found that physician behaviors and patient/family perceptions of that behavior were associated with improved asthma outcomes in pediatric patients. The patient/family perceptions included "worries were relieved," the doctor attended to concerns, spent enough time and was thorough (Clark et al., 2008).

This relationship has also been described as essential to the best medical care. A positive relationship between the provider and patient/family "affords a sense of shared goals and mutual positive regard, as well as lack of negative behavior that potentially could undermine the relationship and the treatment (Gavin, Wamboldt, Sorokin, Levy,

Wamboldt, 1999, pg. 355)." It was proposed in a National Cancer Institute monograph that the PPR can lead to improved health through at least seven avenues. These avenues are outlined in the below paragraphs.

*Access to Needed Care*

Many times barriers to access to care are not just economics, but also knowledge. Families may not know that special care or tests are needed or where to get the needed care. The provider must adequately communicate the need for care and facilitate getting this care.

*Increased patient knowledge and shared understanding*

It is obvious that families must understand their child's illness in order to make informed decisions about their child's care. It is less obvious that the provider must understand the family from the perspective of their values and belief system about health (Street et al, 2009). Evidence of the importance of this understanding of the family from the providers' perspective may be found in disparities in care. An Institute of Medicine (IOM) report concluded that among other things that the providers understanding of the patient's cultural and ethnic background and their expectations from the clinical encounter leads to disparities in health care (IOM, 2003).

*Enhancing therapeutic alliances among providers, patient, and family*

A therapeutic alliance is evident when the child's family feels respected and cared for and is achieved through information sharing and provider empathy to the family circumstances (Street et al, 2009). Parents of critically ill children have stated many time

how compassionate, honest and timely interactions with physicians help with decision making in the care of their child (Jones, Contro, Koch, 2014). While this therapeutic alliance has been found to be important, it has been shown that lay beliefs , culture and folk wisdom about specific diseases, can affect treatment compliance in chronic illnesses such as asthma, these topics are rarely discussed in a clinical encounter (Diette, Rand, 2007)

*Enhancing emotional self-management*

The fourth avenue described here, enhancing the patient's ability to manage emotions is, as with much of these, enhanced through clear and honest information sharing, as well as listening to and validating the patient's and family's feelings.

*Activating social support and advocacy resources*

The fifth avenue, improving family and social support, while usually outside of the clinical realm, can be contributed to by the PPR through countered of negative support and providing support through communication.

*Enabling patient empowerment*

It seems fairly obvious that patient empowerment can be enhanced through the PPR. An empowered patient is more likely to have good self-management skills and make better decisions about their health care.

*Increasing the quality of medical decisions*

Finally the seventh avenue better decision making," requires clinical encounters where patients and families and clinicians present and understand one another's perspectives,

find common ground, reconcile differences, achieve consensus on treatment and, when differences cannot be reconciled, negotiate a mutually acceptable plan (Street et al, 2008, pg. 299).” (Street et al, 2008). Multiple studies demonstrate the importance of shared decision making. A study published in 2011 found that in adult asthma patients that shared decision making improved medication adherence and improved outcomes (Desai, Oppenheimer, 2011). An additional study found that in children with asthma, when the caregiver was asked for input in the medical treatment plan that reported medication adherence was improved (Sleath et al, 2012).

**Shared Decision Making**

Shared decision making was identified by the Institute of Medicine as a priority comparative effectiveness research topics and the 2010 Patient Protection and Affordable Care Act places an emphasis on programs that facilitate shared decision making (IOM, 2009; PPACA, 2010). Some studies suggest that FCC facilitates shared decision making (IPFCC, 2010; Strickland et al, 2004). Shared decision making has also been described as “an essential element of patient-centered care (Chong, Aslani, Chen, 2013)” and the “pinnacle of patient-centered care (Barry, Levitan, 2012). It has been suggested that shared decision making depends on a trusting relationship between caregivers and providers (Alston et al, 2012; Ferrer, Gill, 2013). When faced with decisions about treatment options, patients want to be partners in their health care (Guadagnoli, Ward, 1998). While SDM depends upon a trusting relationship and also may enhance SDM; it also may contribute the patient taking on a more passive role (Entwistle, 2004). A study published in 2013 demonstrated this relationship where children receiving care described a family centered were more likely to have a family perception of shared decision making

(Smalley, Kenny, Denbobo, Strickland, 2013). Additionally Schoenthaler et al reported in 2009 that in hypertensive African American Patients, provider communication that was described a collaborative was associated with better adherence to anti-hypertensive medications. Croom et al reported in 2011 that patient-centered communication with diabetic adolescents and their families had greater perception of control and competence to manage their disease. This type of communication was described as a style of communication between healthcare providers and patients that includes partnership building, empathy, interpersonal sensitivity, and mutual exchange of information (Erickson, Gerstile, Feldstein, 2005). Additionally, this was found to be indirectly related to adherence to treatment and metabolic control (Croom et al, 2011).

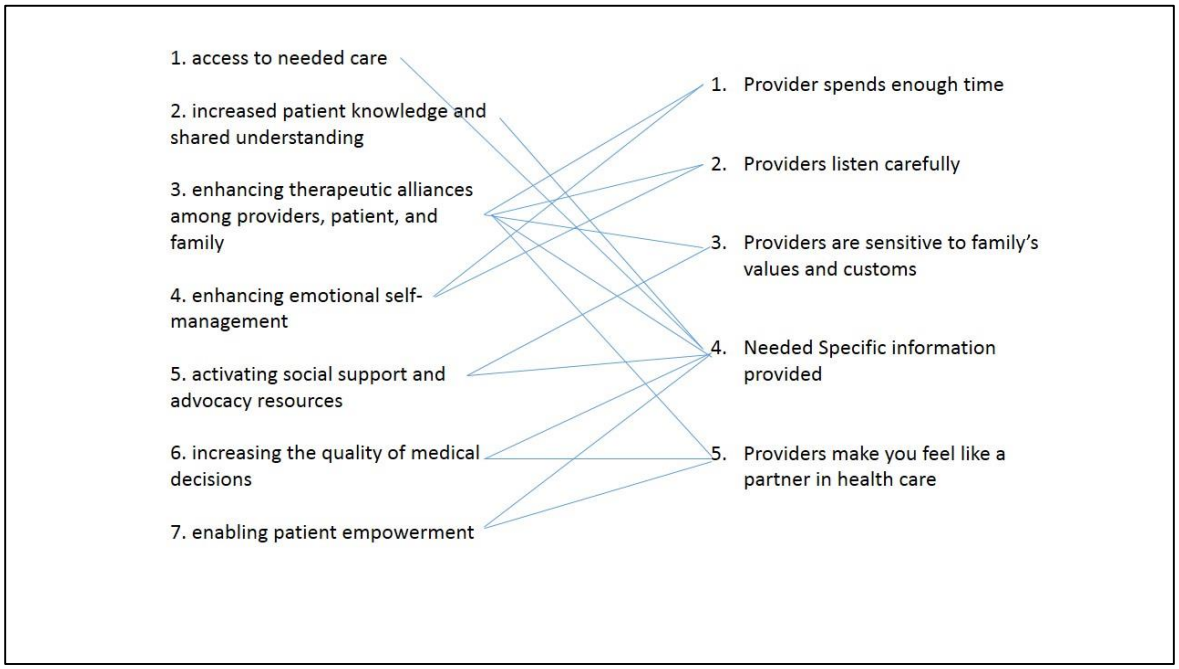


**Figure 2.1 The Relationship of the PPR to Family-Centered Care**

**Family-Centered Care and the PPR and Asthma**

In the most recent guidelines for the diagnosis and management of asthma by the National Heart and Lung Institute the patient provider relationship is highlighted as a key component in effective management of asthma. Specifically the guideline recommends that a partnership between the patient and provider be both established and maintained. "Building a partnership requires that clinicians promote open communication and ensure that patients have a basic and accurate foundation of knowledge about asthma, understand the treatment approach, and have the self-management skills necessary to monitor the disease objectively and take medication effectively (EPRP-3, 2007, pg. 124)." This basic foundation of knowledge and its ability to modify disease treatment and outcomes is demonstrated by Haln et al (2006), when they determined that more than half of adults admitted to a New York hospital with asthma and who also have a long history of severe asthma including hospitalizations and intubation, i.e. frequent contact with the health care system, believe that their asthma is episodic. They believe that when they do not have symptoms, they do not have asthma. These same patients also are less likely to take their daily prescribed anti-inflammatory medicine. While the direct cause of this may not be patient education, it does underscore the importance of the patient provider relationship and the importance of good communication in the patient provider encounter (Hahn, Leventhal, 2006). Some caregivers, while believing that there children need their medication to control their asthma, also have fears and concerns about the side effects and the stigma attached to using daily medication. This leads to lack of adherence to medication dosing regimens and in turn, leads to exacerbation of asthma symptoms. These fears can be addressed as part of a good patient/provider relationship and good

communication at the time of prescription, as well as in follow-up visits (Con et al, 2005). Studies have demonstrated that medication adherence is enhanced when the patient can easily communicate with their physician (Apter, Reisine, Affleck, 1998), the physician spends enough time with the patient (Adams, Weiss, Fuhlbrigge, 2003), and understands how the patient views his illness (Lindberg et al, 2001).

Some studies have suggested that caregivers describe a good provider relationship as one where the provider is a good listener and a good educator and spends enough time with the caregiver and the child. When the provider was described as above, it is more likely that the caregiver will have a good understanding of asthma management and will follow-through with appropriate care (Valerio, Cabano, White, Heidmann, Brown, Bratton, 2006). However, there are barriers to getting the most out of the patient provider relationship. These include health beliefs and knowledge and expectations about care (Seid, 2008).

In asthma care, the provision of a long term treatment plan, is a very important aspect of the patient/provider partnership. This somewhat simple, interaction between patient/family and the provider encourages fuller involvement by the patient and family and "may even provide the patient with "light at the end of the tunnel" in the form of a future with less medicine, fewer symptoms, and fuller functioning (Clark et al, 2008, pg.56)" (Clark et al, 2008).

Patient provider communication has been shown to affect adherence with medication. The lack of adherence to medication is a leading cause of increased morbidity in asthma, including increased ER visits and hospitalizations, as well as

decreased quality of life. Apter et al (1998), found that patients who are comfortable in talking with their physician; whose physicians provided them with education; and who can easily see their physician when needed were more likely to adhere to prescribed twice daily use of inhaled steroids.

Some studies note an under-estimation of asthma severity by the provider when they rely upon patient-reported symptoms. One such study concluded that 60% of children with asthma had their asthma severity underestimated by their provider, with most of these children not being prescribed maintenance medication due to this under-estimation. The study concluded that this underestimation was more than likely related to the patient-physician relationship (Halterman et al, 2002). It has also been demonstrated that providers who simply inquire about daytime and nighttime symptoms and exercise impairment and school absenteeism can accurately determine asthma severity almost 100% of the time (Cowen, Wakefield, Cloutier, 2007). This requires an ongoing, trusting relationship between the caregiver and the provider.

Additionally, studies have suggested that the underestimation of asthma severity contributes to racial disparities in asthma care. Okelo et al (2007) found that providers more often underestimated asthma severity of blacks than whites. This led to poorer management of the disease. These patients were also less likely to rate their communication with the provider as good or the care as quality care. A study by Newcomb et al. published in the *Journal of Asthma,* in 2010, suggested that in adult asthma patients barriers to adequate treatment included difficulty in establishing and maintaining a therapeutic relationship with a clinician. This inability to establish this relationship was primarily driven by communication failures. These communication

failures included dissatisfaction of direct communication with the clinician, including time constraints. Patients also tended to conceal symptoms unless asked by the clinician.

Clark et al, through a study of physician behavior and children with asthma, predicted that when physicians were regarded as thorough and relieved the worries of their patients' caregivers, that there was a reduction in ED visits, urgent office visits and hospitalizations. These were children with active asthma, as defined by having at least one urgent office visit, ED visit, or hospitalization in the past two years due to asthma (Clark et al., 2008). Similarly, Cabana et al (2006) found that in children with asthma receiving care from physicians that had completed a continuing medical education program to improve asthma therapeutic and communication skills, had significantly fewer ED visits, and fewer days where activity was limited by asthma related symptoms. Caregivers of these children also were more likely to note that the physician "found out the parent's biggest worries", informed the parents that the child can be fully active, and "ask if the child met specific goals including no daytime symptoms, no nighttime symptoms, and no limitation in activity."

A very small qualitative study of adults with severe/difficult asthma, conducted in the United Kingdom, suggested that these patients were more likely to have poorer relationships with healthcare providers and would describe these relationships as paternalistic or authoritarian (Moffat, Cleland, Molen, Price, 2006). It has been shown that physician characteristics such as values incongruent with the caregiver, being hurried and insensitive to complaints leads to underutilization of health care services (Mangan, Wittich, Gerald, 2007). Caregivers of children with asthma have cited lack of family-centered care and/or poor provider relationships as contributors to poorer asthma

outcomes. Lack of communication or ineffective communication between provider and care giver sometimes leads to the caregiver modifying the treatment plan based on their own beliefs, not what the provider has told them. They also cite that a positive relationship with a provider allows for better quality care (Laster, Holsey, Shendell, McCarty, Celano, 2009). Other studies indicate that barriers to positive asthma outcomes included the amount and quality of information that families received about asthma; lack of time spent with child, failure for the provider to listen to the caregivers, and cultural incompetence (Rose,Garwick 2003).

Some studies have suggested that ED use for asthma in children is related to poor communication or lack of communication with primary care physicians, as well as the lack of management treatment plans and preventive measures (Fredrickson, Molgarrd, Dismuke, Schukman, Walling, 2004). Additionally, poor management and preventive measures that decrease exacerbations results in increased ER visits and hospitalizations. This makes it evident that increasing family competence in caring for their child with asthma and providing care that meets the needs of the family, i.e. family-centered care, will decrease ED use as well as hospitalizations (Diedhiou, Probst, Hardin, Martin, Xirasagar, 2010).

**Family-Centered Care and Outcomes**

FCC is increasingly being considered a key to quality health care. It also has been shown that it leads to greater patient/family satisfaction, as well having a positive effect on health related behaviors. Patient and/or family centered communication has been shown to have beneficial effects on outcomes. This is believed to be a result of better

engagement of patients and families in their own healthcare and treatment (Michie,Miles, Weinman, 2003). While, FCC is considered a key to quality health care, there is still limited research that looks specifically at this process of care and its relationship to outcomes.

Some studies have only looked at some components of FCC. Denbobo et al (2006) found that among children with special health care needs, 85.8% of their families reported feeling like a partner in their child's care. Families who reported feeling like a partner only sometimes or never, were 1.22 times more likely to miss school, 3.73 times more likely to not get specialty care, 9.15 times more likely to be dissatisfied with services, 2.54 times more likely to have unmet child needs and 2.69 more likely to having unmet family needs, as compared to families who report they usually or always feel like a partner. This study utilized the 2001 National Survey of Children with Special Health Care Needs (NS-CSHCN). This study used the question in the survey, "in the past 12 Months how often did your child's doctor or health care providers help you like a partner in his/her care?" A response of "usually" or "always" was classified as having a partnership with their child's health care provider. This sense of partnership is only one of five components of family centered care, but it does highlight the very important aspect of family/provider partnerships and its principles.

> "Family-Centered care assures the health and well-being of children and their families through a respectful family-professional partnership. It honors he strengths, cultures, traditions, and expertise that everyone brings to this relationship. Family centered care is the standard of practice which results in high

quality services…The foundation of family-centered care is the partnership between families and professionals (Bishop, Woll, Arango, 2004)."

Kenney et al had similar findings in a study published in 2011. This study utilized the 2005-2006 National Survey of Children with Special Health Care needs. They, like Denbobo et al, for the partnership component used responses of usually or always to the questions "in the past 12 months, how often did your doctors or health care providers help you feel like a partner in his/her care?" They found that attainment of the core outcome of both feeling like a partner in their child's care and being satisfied with that care, was associated with several positive outcomes including fewer school absences, higher rates of getting needed referrals and reduced rates of unmet child and family health needs (Kenney, Denbobo, Strickland, Newacheck, 2011).

Knapp et al (2010) studied this same partnership relationship to outcomes. This study utilized the 2005-2006 NS-CSHCN and responses to the question "How often did your child's doctor and other health care providers' help you feel like a partner in his/her healthcare?" A response of usually or always indicated a partnership, while a response of sometimes or never indicated a lack of partnership. This partnership was found to reduce emergency department visits by 20% and missed school days by 9.4%. They did not find an association between partnership and number of doctor visits. Limitations of all of these studies s included only using one variable as indication of the family-provider relationship, even though there are multiple questions that could more thoroughly assess this aspect of care. Our planned study will use all 5 of the components of this relationship.

Multiple studies have examined the impact of the medical home on outcomes. FCC is a core component of a medical home. In 2010 another study utilizing the NS-CSHCN suggested that there is an inverse relationship between the presence of a reported medical home and emergency department (ED) visits among children with asthma. This study examined the whole concept of a medical home including that care not only be family centered, but also coordinated, accessible, continuous and comprehensive. This study utilized the six questions relative to family-centered care and assigned a value of "yes" if the questions were answered usually or always to each of the questions. (Diedhiou et al, 2010).

A few studies have examined outcomes relative to FCC, usually in the context of care received in a medical home. In 2012 a study utilizing the 2005-2006 NS-CSHCN demonstrated that family-centered care contributed to lessening the burden of children with Type 1 diabetes on families. Katz et al. reported in the Journal of Pediatrics in 2012 that families of children with Type 1 diabetes had fewer work restrictions, as defined by stopping or cutting down on work and financial impact if they received family centered care as measured by answering usually or always to the 5 measures of FCC in the NS-CSHCN (Katz, Laffel, Perrin, Kuhlthau, 2012). Kuo et al. (2010) published research that examined associations of family-centered care and health care outcomes in children with special health care needs. In this study the conceptual framework was based on Andersen's health services utilization model and used FCC as a contextual factor. This was based on the notion that FCC principles refer to provider behaviors and actions. This study utilized the 2005-2006 NS-CSHCN and measured FCC by utilizing the five questions that focused on how well providers met family concerns, how much time was

spent with them, listening, sensitivity to family values, information sharing, and forming partnerships. If all 5 questions were answered "usually" or "always", care was considered family-centered. This index of family centered care was created with the same cut points as used by the Maternal Child Health Bureau to measure family centered care. The study found that nearly 66% of all respondents reported receiving FCC. This study also found a number of positive associations between FCC and outcomes. This included reduced family burden and stable child health, as well as less emergency department (ED) visits.

Turchi et al (2009), found an indirect relationship between FCC and positive outcomes. This study published in 2009 found an association between children who experience good care coordination and receipt of family centered care. This study utilized the NS-CSHCN and found that those children with special health care needs, defined as "having a chronic physical, developmental, behavioral, or emotional condition who require health and related services of a type or amount beyond that required by children generally (Newacheck, 1998)," who reported good case coordination, had an increased odds of receiving family-centered care, feeling like a partner with providers, and greater satisfaction with services. In addition those who reported good case coordination also had decreased odds of having more than 2 ED visits and of missing more than 6 school days because of illness in the last year (Turchi et al, 2009).

Another study published in 2014 demonstrated this same positive relationship between having care coordination needs met and FCC among children with mental disorders. This study utilized the 2007 National Survey of Children's Health and the

same measures of FCC as in the above studies (Brown, Green, Desai, Weitzman, Rosenthal, 2014).

Care coordination is important for many reasons, but relative to our study, it has been demonstrated to reduce emergency department use and hospitalizations (Antonelli, Stille, Antonelli, 2008). An additional study, demonstrated that children with special health care needs who also reported receiving family centered care, were more likely to have care coordination needs met, than those not receiving FCC. Family centered care also attenuated the racial and ethnic disparities in receipt of care coordination. This study utilized the 2007 National Survey of Children's health and the 5 principles of FCC as all studies above (Toomey, Chien, Elliott, Ratner, Schuster, 2013).

Similarly, Farmer et al, found that children with autism spectrum disorders were less likely to have unmet child specialty care needs if they reportedly received family centered care. This was part of a study looking at the impact of a medical home. This association of FCC was determined by similar questions as in the above studies. These questions were provider spends enough time, listens carefully, sensitive to family values, provides needed information and partners with family. This study however utilized a small (371) group of families recruited from the Interactive Autism Network, an online registry for individuals with Autism Spectrum Disorder (Farmer et al, 2013). Also in children with ASD, a similar study as the Farmer study above, found that the higher degree of perceived family-centered care that was received was associated with the perceived provision of more comprehensive care (Carbone, Murphy, Norlin, Azor, Sheng, Young, 2012).

Family centered care has also been associated with a sense of shared decision making. An analysis of the 2009 NS-CSHCN demonstrated that families who reported family centered care were nearly 10 times as likely to report a sense of shared decision making. Shared decision making has been identified as one of the IOM's priorities in comparative effectiveness research and the 2010 Patient Protection and Affordable Care Act emphasizes among other things the support of programs that facilitate SDM (Kenney, Denbobo, Strickland, 2013).

## Study Purposes

This study, the first to our knowledge, will examine the effects that routinely receiving family-centered care has on specific asthmas outcomes, as well as the distinction between FCC and SDM, as measured in the 2009-2010 NS-CSHCN, if there is one. Hypotheses, related to this study are presented in Chapter 3.

### *Study 1 Family-Centered Care and Shared Decision Making*

Childhood asthma, in most cases is not preventable, but can be controlled. Treatment adherence is one area that helps control asthma exacerbations and excess morbidity. Studies have shown that patients are more likely to comply with asthma treatment when a treatment plan is discussed and there is shared decision making between the patient/family and the provider, about what may work best for the patient. However, it is not clear that shared decision making is a separate construct from family-centered care. If it is the same construct as Family-centered care, it should possibly be included along with other measures to more accurately determine actual perceived receipt of family-centered care. This study will examine the five measure of FCC the provider's

time spent, listening carefully, sensitivity to family's values and customs, receipt of needed information, and feeling like a partner in child's care and the four SDM measures of providers discussing treatment options, encouraging questions, making it easy to ask questions, and respecting the treatment choices that the family makes to try to ascertain if these two are different constructs.

***Study 2 Receipt of all needed prescription drugs and ED Visits***

Childhood asthma, in most cases is not preventable, but can be controlled. Treatment adherence is one area that helps control asthma exacerbations and excess morbidity. A main stay of treatment is the use of prescription medications. This study will attempt to determine if the receipt of family-centered care is associated with the receipt of all needed prescription medication. Family Centered Care will be measured by answering always or usually to five questions regarding the provider's behavior; time spent, listening carefully, sensitivity to family's values and customs, receipt of needed information, and feeling like a partner in child's care. This study will also examine the association of the four measures of shared decision making relative to the same outcomes as above and will compare the two.

Childhood asthma is characterized by episodes of wheezing, chest tightness, and coughing and if not well controlled can be life threatening and thus results in frequent ED visits for many. This study will attempt to determine if the receipt of family-centered care reduces the number of ED visits. Family Centered Care will be measured by answering always or usually to five questions regarding the provider's behavior; time spent, listening carefully, sensitivity to family's values and customs, receipt of needed

information, and feeling like a partner in child's care. This study will also examine the association of the four measures of shared decision making relative to the same outcomes as above and will compare the two.

# CHAPTER 3

# RESEARCH METHODS

## Research Questions and Hypotheses

### Study 1

Research Question: In children with asthma, are measures of family-centered care and measures of shared decision making, as found in the 2009-2010 NS-CSHCN, separate constructs?

H1: Measures of family-centered care and measures of shared decision making, as found in the 2009-2010 NS-CSHCN share the same underlying construct.

### Study 2

Research Question 1: In children with asthma, is care in the ambulatory setting that is perceived as family-centered and experiencing shared decision making, associated with the receipt of all needed prescription medication?

*H*1: Receipt of family-centered care and shared decision making are positively associated with the receipt of all needed prescription medication.

Research Question 2: In children with asthma, is care in the ambulatory setting that is perceived as family-centered and is shared decision making, associated with fewer annual Emergency Department Visits?

*H*1: Receipt of family-centered care and shared decision making is inversely related to the number of annual ED visits.

## Methods

This study will utilize the 2009-2010 National Survey of Children with Special Health Care Needs (NS-CSHCN). This survey was primarily sponsored by the United States Department of Health and Human Services (DHHS), Health Resources and Services Administration (HRSA), and Maternal and Child Health Bureau (MCHB). Data was collected between July 7, 2009 and March 2, 2011.

The NS-CSHCN was designed as a cross-sectional telephone survey of US households with at least one resident child aged 0 to 17 years at the time of the survey. It utilized a list-assisted random-digit dial (RDD) sample of landline telephone numbers and this was supplemented with a RDD sample of cell phone numbers. Each telephone number was called and screened for residency and the presence of a child aged 0 to 17 at the time of the call. All children living in the household were screened for special health care needs. If more than one child in the household had special health care needs, one was chosen randomly for the interview. The screener used to identify children with special health care needs is designed to reflect MCHB definition; "Children with special health care needs are those that have …a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally (McPherson et al, 1998)." Respondents for the survey were a parent or guardian with knowledge of the health and health of the children in the household. A total of 372,698 children were screened and detailed interviews were completed for 40,242 CSHCN representing all 50 states of the United States.

## Sample

The sample for both studies is children age 0 to 17 that currently have asthma. To be included, respondents had to answer positively on interview, "Does [S.C.] currently have asthma.' A query of the NS-CSHCN, yielded 13,144 children that currently have asthma.

## Conceptual Framework

The overall conceptual framework for both studies is Donabedian's classic structure/process/outcomes framework for assessing health care quality. In Donabedian's framework structure refers to the setting in which care is received and includes such things as organizational structure, culture, and also information technology (Edwardson, 2007). Structure can also include such things as qualifications of care providers, as well as patient characteristics (Elverson, Samra, 2012) Process refers to how and what care is delivered and how it is received and finally outcomes refers to the health status of a person as a result of the care that is received. Outcomes are not only those technical outcomes like prevention of complications, but also patient satisfaction or a patient's perceived quality of care that is based on interpersonal relationships between the provide perceived quality of care that is based on interpersonal relationships between the provider and the patient. Donabedian also asserted that structure, process and outcome are not independent but are dependent on one another (Donabedian, 1988).

In addition to Donabedian, the conceptual framework for Study 2 is based upon Andersen's (1995) Behavioral Health Model. This model indicates that the health care system is dependent upon multiple factors that are described as predisposing

characteristics, enabling resources and perceived and/or actual need. The factors are influenced by the system of care available (Andersen, 1995, 2008).

Further, the conceptual framework for both studies is also based upon the biopsychosocial model of health care. It is a model that considers all the biological, social and psychological factors that influence health. See Figure 3.1 for the Conceptual Model.

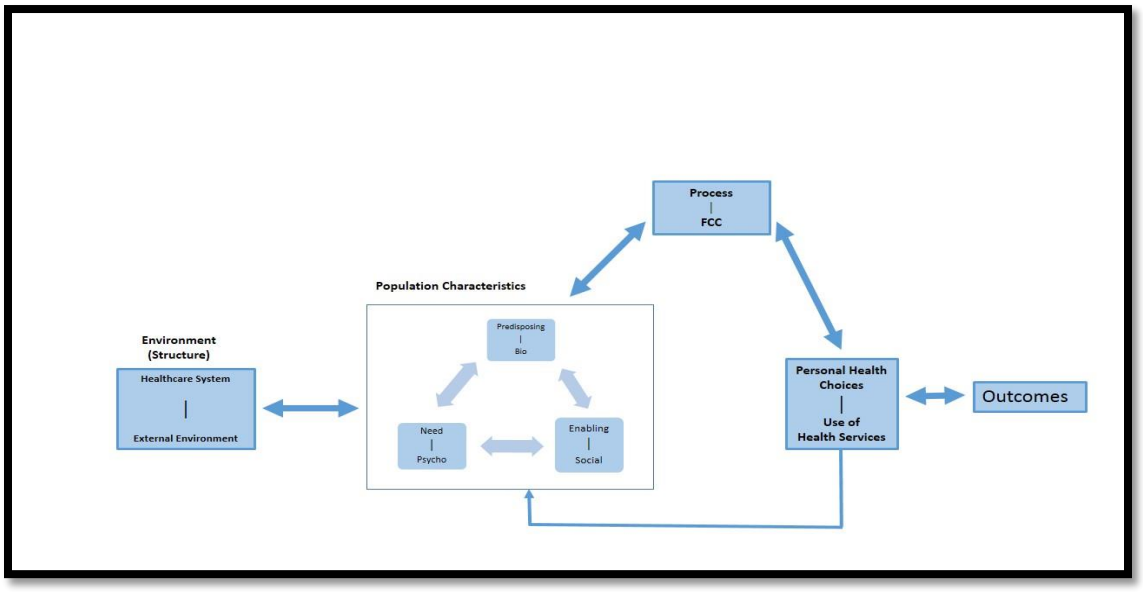


**Figure 3.1 Conceptual Model**

## Independent Variables

The independent variable for study 2 will be the receipt of family centered care. Family centered care will be considered to be present if parents answer (Coker et al, 2010; Drummond et al, 2011; Ngui and Flores, 2006) "always" or "usually" to the following 5 questions:

1. [During the past 12 months / since [his/her] birth], how often did [S.C.]'s doctors and other health care providers spend enough time with [him/her] ?
2. [During the past 12 months / since [his/her] birth], how often did [S.C.]'s doctors and other health care providers listen carefully to you?
3. When [S.C.] is seen by doctors or other health care providers, how often are they sensitive to your family's values and customs?
4. During the past 12 months / since [his/her] birth], how often did you get specific information you needed from [S.C.]'s doctors or other health care providers?
5. During the past 12 months / since [his/her] birth], how often did [S.C.]'s doctors and other health care providers help you feel like a partner in [his/her] care?

These 5 questions were derived partly from the Consumer Assessment of Healthcare Providers and Systems (CAHPS) survey and partly by the American Academy of Pediatricians in the framework of the Medical Home Model (Reinke, 2013). These five questions have also be found to be quite reliable with an alpha of 0.84 (Drummond et al, 2011).

Additionally, we will look at the four measures of shared decision making and compare to the same outcomes and then compare to FCC. The four measures of SDM are as follow:

1. "[During the past 12 months / since [his/her] birth], how often did [S.C.]'s doctors or other health care providers discuss with you the range of options to consider for [his/her] health care or treatment?"

2. "[During the past 12 months / since [his/her] birth], how often did [ S.C.]'s doctors or other health care providers encourage you to ask questions or raise concerns?"
3. "[During the past 12 months / since [his/her] birth], how often did [S.C.]'s doctors or other health care providers make it easy for you to ask questions or raise concerns?"
4. "[During the past 12 months / since [his/her] birth], how often did [S.C.]'s doctors or other health care providers consider and respect what health care and treatment choices you thought would work best for [S.C.]?"

For each question an answer of "always" or "usually" will indicate that parents perceived themselves as sharing in decision making with their child's health care providers. Responses of "sometimes" or "never" will indicate that parents do not perceive themselves as sharing in decision making with their child's health care providers. These four measures together provide for a composite variable of shared decision making. Answers of "always" or "usually" to all four questions demonstrate that parents perceive themselves as sharing in decision making. These four variables have been tested with parents of CSHCN and showed to have face validity, were understood as intended and reliable. Cronbach's Alpha for the SDM items was 0.868, indicating high internal consistency. Item correlations demonstrated linked, but differentiated, information is provided by each item with correlations ranging from 0.592 to 0.686. Corrected item-total correlations ranged from 0.679 to 0.765 indicating each item is correlated with the measure as a whole (Smalley, Kenny, Denbobo, Strickland, 2013).

**Variable definitions**

The primary outcome measures of Study 2 will be number of annual ED visits and the receipt of all needed prescription drugs in the past year. ED visits will be measured by the answer to the following question:

> "During the past 12 months/ since [his/her] birth, how many times did [S.C.] visit a hospital emergency room?"

ED visits will be coded a dichotomous variable: 0 and 1+ visits.

The receipt of all needed prescription drugs will be measured by the answer to the following question:

> "Did [S.C.] receive all the prescription medication that [he/she] needed?"

The receipt of all needed prescription drugs will be coded as a bi-level variable yes or no.

The predisposing characteristics that will be held constant for study 2 are the child's age, gender, race/ethnicity, highest education level of parent or guardian, and family structure. Age will be coded as a three level categorical variable: 0 to 5 years, 6 to 11 years and 12 to 17 years (Diedhiou et al, 2010). The highest education level will be coded as a three level categorical variable: less than high school, high school graduate, and more than high school. Family structure will coded as a three level categorical variable: Two parent family, single mother with no father present, and other. Race/ethnicity will be coded as a three level categorical variable: White, Black and other.

The enabling characteristics that will be held constant for study 2 are income and insurance status. Income as measured by percent of federal poverty level (FPL) will be coded as a three level categorical variable: 0% to 200% of FPL; 201% to 400% FPL, and

greater than 400% of FPL. Missing income information will be included in the analysis. Insurance status will be coded as a four level categorical variable: Private insurance, public insurance, uninsured and other.

The need characteristic that will be held constant for study 2is breathing difficulties. Breathing difficulty will be measured by the answer to the following question:

> "Would you say [he//she] experiences a lot, a little or no difficulty with breathing or other respiratory problems, such as wheezing or shortness of breath?"

Breathing Difficulty will be coded as a three level categorical variable: a lot of difficulty, a little difficulty, and no difficulty. In addition, in study 2, when measuring ED visits, the receipt of all needed prescription drugs will be held constant as a need characteristic. It will be coded as a two level categorical variable: yes did receive, or no, did not receive all needed prescription medications.

**Analysis**

All analysis will be conducted with SAS v. 9.4.

**Study 1**

Factor Analysis will be performed for the 9 variables representing FCC and SDM. A split dataset of children with asthma will be utilized to conduct the analysis. If it is determined that FCC and SDM are the same construct, the validity and consistency of a new measure of FCC,that includes SDM will be tested.

**Study 2**

Bi-variate analysis will be used to compare categorical variables. Chi square tests will be used to determine independence. Multivariable logistic regression models will be run with each of the outcomes, ED visits and receipt of all needed medication, as the dependent variables. Receipt of family centered care will be the primary independent variable for both outcomes. Co-variants (predisposed, enabling and need) will be studied for confounding and interaction among co-variants and outcomes.

# CHAPTER 4

## MEASURES OF FAMILY-CENTERED CARE AND SHARED DECISION MAKING: ARE THEY THE SAME CONSTRUCT? [1]

[1] Brumbaugh B.L., Probst J.C., Hale N. L., Xirasagar S., Hardin J. W., Wagner P.J. to be submitted to *Maternal and Child Health*

## Abstract

**Objective**: We evaluated the measures of Family-Centered Care (FCC) and the measures of Shared Decision Making (SDM) utilized in the 2009-2010 National Survey of Children with Special Health Care Needs (NS-CSHCN), to determine if they represent two different constructs, in children with asthma.

**Methods:** We executed an exploratory principal factor analysis of the five survey items representing measures of family-centered care and the four items representing measures of shared decision-making. A split dataset of children with asthma was utilized to conduct the analysis.

**Results:** Correlations among the nine items ranged from 0.38 to 0.67. This demonstrated related, but distinct, information being provided by each variable. This one model explains 46.9% of the variance between the variables. Further analysis yielded a Cronbach's Alpha of 0.912, indicating high internal consistency for these nine variables measured together as one construct.

**Conclusions:** Our findings conclude that the measures found in the NS-CSHCN for FCC and SDM belong to one overarching construct, which we contend is more indicative of the broader concept of FCC. Our findings further indicate that additional research is needed on measurement tools for PFCC, that more fully address all aspects of this important care process, including SDM. Our findings should be validated by additionaresearch that explores the relationship of FCC and SDM, as found in the 2009-2010 NS-CSHCN, and their associations with specific outcomes.

## Introduction

Family-Centered Care (FCC) as affirmed by the American Academy of Pediatrics (AAP) is considered the standard of care in pediatrics, which includes pediatric care delivered within the ambulatory care setting. The construct of FCC is centered on information sharing, respect, partnership, and care in context with family needs (Kuo, Houtrow, Arango, Kuhlthau, Simmons, 2012). Studies have suggested that FCC or Patient-and Family-Centered Care (PFCC) is a multidimensional framework including dimensions of shared responsibility and the patient/provider relationship (Mead&Bower, 2000; Howie, Heaney, Maxwell, 2004; Hudon et al, 2011). Questions aimed at measuring receipt of FCC are included in several national surveys, including the Consumer Assessment of Healthcare Providers and Systems (CAHPS), National Survey of Children's Health (NSCH), and the National Survey of Children with Special Health Care Needs (NS-CSHCN). Of particular interest to this study is the inclusion in the NS-CSHCN. This survey is administered by the Maternal and Child Health Bureau and illuminates the care experiences of vulnerable children and their families, including those related to FCC.

More recently, implementation of reforms contained within the 2010 Patient Protection and Affordable Care Act (PPACA) have placed an increasing emphasis on the role of shared decision-making (SDM) between families and providers in the care process. As a result, the Maternal and Child Health Bureau established SDM as one of its core outcomes for children with special health care needs. This focus is evidenced by the addition of four specific measures of SDM in the 2009-2010 National Survey of Children with Special health Care Needs (NS-CSHCN).

The active use of these two constructs (FCC and SDM) separately within the same survey would imply that they represent separate constructs aimed at measuring differing aspects of the care experience. This implication is further supported by the use of the measure of SDM in recent research that examined shared decision-making and outcomes (Butler, Elkins, Kowalkowski, Raphael, 2014; Smalley et al, 2013). However, the key themes embedded within these constructs are very similar and the extent to which shared decision-making (SDM) represents a separate construct from the existing FCC construct warrants further investigation to clarify the use of the measures.

One population particularly amenable for investigating the application of these constructs is among children living with Asthma. Asthma is the most common chronic disease among children, affecting over 12% of children (Mattke et al, 2009). In 2004, the total estimated cost of treating asthma in the United States (adults and children) exceeded $16 billion, with hospital care accounting for $11 billion of this cost. Great advances in the treatment of asthma have been made, especially with pharmacotherapy. However, 74% of children with moderate to severe asthma still do not receive adequate treatment (Mattke et al, 2009). This is a significant public health burden, not only on the children's caregivers, but also on schools, employers and the health care system.

Our study sought to examine the distinction between FCC and SDM by determining the extent to which they represent differing constructs among children living with Asthma. Specifically we examined the degree to which the five survey items measuring FCC and the four survey items measuring SDM found in the 2009-2010 represent different constructs or conversely measure the same dimension of FCC. Healthcare reform places emphasis on quality improvement and performance measures,

which underlies the importance of our research. These factors will continue to drive change in policy and it is increasingly important that we measure quality initiatives and processes of care properly.

**Methods**

This study utilized the 2009-2010 National Survey of Children with Special Health Care Needs (NS-CSHCN). This survey was primarily sponsored by the United States Department of Health and Human Services (DHHS), Health Resources and Services Administration (HRSA), and Maternal and Child Health Bureau (MCHB). Data was collected between July 7, 2009 and March 2, 2011.

The NS-CSHCN was designed as a cross-sectional telephone survey of US households with at least one resident child aged 0 to 17 years at the time of the survey. It utilized a list-assisted random-digit dial (RDD) sample of landline telephone numbers and this was supplemented with a RDD sample of cell phone numbers. Each telephone number was called and screened for residency and the presence of a child aged 0 to 17 at the time of the call. All children living in the household was screened for special health care needs. If more than one child in the household had special health care needs, one was chosen randomly for the interview. The screener used to identify children with special health care needs is designed to reflect MCHB definition; "Children with special health care needs are those that have …a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally (McPherson et al, 1998)." Respondents for the survey were parents or guardians with knowledge of the health and health of the

children in the household. A total of 372,698 children were screened and detailed interviews were completed for 40,242 CSHCN representing all 50 states of the United States.

**Measures**

Family-Centered Care. In the survey, the following five questions were used to measure family-centered care. Responses are on a 4-point Likert scale with responses of always, usually, sometimes and never.

1. [During the past 12 months / since [his/her] birth], how often did [S.C. (Subject Child)]'s doctors and other health care providers spend enough time with [him/her]?
2. [During the past 12 months / since [his/her] birth], how often did [S.C.]'s doctors and other health care providers listen carefully to you?
3. When [S.C.] is seen by doctors or other health care providers, how often are they sensitive to your family's values and customs?
4. During the past 12 months / since [his/her] birth], how often did you get specific information you needed from [S.C.]'s doctors or other health care providers?
5. During the past 12 months / since [his/her] birth], how often did [S.C.]'s doctors and other health care providers help you feel like a partner in [his/her] care?

The survey also has the four following separate questions to measure shared decision-making. Responses are on a 4-point Likert scale with responses of always, usually, sometimes and never.

1. "[During the past 12 months / since [his/her] birth], how often did [S.C.]'s doctors or other health care providers discuss with you the range of options to consider for [his/her] health care or treatment?"
2. "[During the past 12 months / since [his/her] birth], how often did [ S.C.]'s doctors or other health care providers encourage you to ask questions or raise concerns?"
3. "[During the past 12 months / since [his/her] birth], how often did [S.C.]'s doctors or other health care providers make it easy for you to ask questions or raise concerns?"
4. "[During the past 12 months / since [his/her] birth], how often did [S.C.]'s doctors or other health care providers consider and respect what health care and treatment choices you thought would work best for [S.C.]?"

**Analysis Approach**

A split dataset of children with asthma was utilized to conduct the analysis, dividing purposively on the assigned number for the child's state of residence. All analyses were initially conducted on a subset of children from states 1-25. To confirm our results, the same analysis was performed on a subset of children representing states 26-51.The N for subset 1 was 6,248 and for subset 2 was 6,407. All analysis were performed using SAS 9.4.

To test the position that FCC and SDM are separate constructs, a principle factor analysis with squared multiple correlations for the prior communality estimates and with PROMAX (oblique) rotation and a two-factor extraction was requested. Correlation coefficients were also calculated for each of the variables included.

To examine further the relationship between the measures of FCC and SDM we conducted a second analysis. We again requested a principal factor analysis, with squared multiple correlations for the prior communality estimates and with PROMAX rotation. However, we did not specify the number of factors to extract, but instead allowed for mathematical determination. SAS uses a maximum eigenvalue (1) by default to identify latent factors. To validate these results we carried out the same analysis on the second subset of children with asthma. To estimate reliability of using all nine variables together as a single measure, a Cronbach's alpha was estimated.

**Results**

Correlations among the nine variables, ranged from 0.38 to 0.67 (Table 4.1). This finding demonstrated similar, but differentiated, information is provided by each item. "Spends enough time" had the lowest correlation and "Encourages questions had the highest correlation among the variables. "Easy to ask questions" and "encourages questions" were highly correlated with each other. "Feels like a partner in healthcare" and "respects treatment choices" were also highly correlated with each other.

Our initial principal factor analysis requested two factors to determine if the measures of FCC and SDM do represent two underlying dimensions As shown in Table 4.2, only one factor had an Eigenvalue greater than one. This finding is further

confirmed by the forced two-factor loadings, shown in Table 4.3. Any factor loading greater than 0.30 is considered significant and equates to approximately 10% overlapping of the variance with the other variables that are correlated. All nine items load on Factor 1 at 0.57289 or higher; the highest value for Factor 2 is 0.21030. When the rotated loading is examined (Table 4.4), all items with the exception of "spends enough time" load at 0.58 or better on both factors, again indicating a lack of separation between the two concepts.

We then completed a second principal factor analysis, but allowing for a mathematical determination of factor loading. Factor patterns demonstrate that all nine variables strongly load (all values greater than 0.3) on only one factor. This one factor explains 46.9% of the variance between the variables and the one underlying factor. For confirmatory analysis, a second random sample (states designated 25-51) of the dataset was analyzed. Table 4.5 provides the comparative Eigenvalues of each data set; table 4.6 provides the comparative factor loading patterns for each. Since the model retained only one factor, rotation analysis was not completed.

Further analysis of the data set representing states 1-25, yielded a Cronbach's Alpha for all nine variables together of 0.912, indicating high internal consistency for these variables measured together as one construct (Table 4.5). Cronbach's alpha measures how well variables explain an underlying construct and values greater than 0.9 demonstrate excellent internal consistency among the variables.

**Discussion**

This is first study, to our knowledge that has examined the measures of FCC and SDM in the NS-CSHCN to evaluate their underlying construct. Our study suggested separating the measurement of shared decision-making from that of FCC may not be possible. This is supported by a study by Franks et al (2005) that developed a patient perceptions survey by conducting factor analysis on four different patient perception scales. These four different scales were a 5-item measure of patient autonomy supportiveness and patient involvement in SDM; a 4-item measure of physician knowledge of the patient; an 8-item trust measure; and a 1-item satisfaction measure. Their factor analysis showed that only one factor emerged that explained 75% of the variance. Using these four scales together in one measure yielded a Cronbach's alpha of 0.88.

Our conclusions differ from those of Kriston et al (2010). These researchers defines a SDM as a model that ensures that providers do not make decisions based solely on scientific evidence, knowledge and experience, but also that their patients are well informed and take part in all aspects of the decision making process. They defined SDM as an interactive process between provider and patient, where information sharing is free flowing, in order to reach a mutually acceptable agreement, that both share equal responsibility. This measure, shown to be reliable, with a Cronbach's alpha of 0.943, asked some questions similar to those found in the NS-CSHCN, such as "my doctor told me that there are different options for treating my medical condition," but also asked very pointed questions, directed at the decision making process, such as "my doctor asked me which treatment option I prefer, my doctor and I selected a treatment option together, and

my doctor and I reached an agreement on how to proceed (Kriston et al, 2010, pg. 98)." This validated survey implies that SDM, while part of PFCC, can be measured separately. Our findings did not support that SDM can be measured separately with the particular questions in the 2009-2010 NS-CSHCN.

We identified two research studies that had used the SDM measure found in the NS-CSHCN. Smalley et al (2013) used the measure to examine the prevalence of SDM among families of children with special health care needs; to determine socio-demographic correlates of perceived SDM; and to assess the associations between SDM and availability of the medical home and/or its components including FCC. They found a significant association between FCC and SDM, with adjusted odds of 9.40 (95% CI 8.54-10.35) that a child receiving family centered care would also experience SDM. Their study also concluded that FCC and SDM are not synonymous, but rather FCC is a health care approach that facilitates SDM. However, this high degree of association between the two measures could also result from both measures tapping the same underlying construct, as suggested by our analysis.

Bultler & colleagues found that the presence of a medical home attenuated differences between SDM for children with mental disorders compared to children with only physical disorders (Butler, Elkins, Kowalkowski, Raphael, 2014). They did not find this same attenuation for children with mental disorders, with comorbid physical disorders. FCC is a component of the medical home; thus their findings are not surprising relative to the results of our analysis.

Patient and family centered care has been described, as a multi-dimensional construct (Mead&Bower, 2000; Howie, Heaney, Maxwell, 2004; Hudon et al, 2011). Mead & Bower (2000) proposed that the conceptual model of patient-centeredness includes five dimensions. These dimensions include "sharing power and responsibility." They contend that each dimension represents distinct aspects of clinical care with their own determinants, correlates, and outcomes. They also acknowledge that these dimensions may overlap, for example information sharing can imply sharing power and responsibility, but may also represent the patient provider relationship known as the therapeutic alliance. A four dimensional model of PCC (patient-center care) was proposed by Hudon et al (2011), that combined the work of Mead & Bower and Stewart et al. These dimensions separate common ground or shared power and responsibility, from the patient-provider relationship or the therapeutic alliance. Epstein et al (2005) describes patient-centered communication as having four domains that includes shared understanding and shared power and responsibility. If a multi-dimensional construct holds true, our findings of only one construct that explains the measures of FCC and SDM, suggests that we may not be measuring all aspects of shared decision making in this survey and alternatively are just measuring SDM aspects of the patient/provider relationship.

However, SDM has been described as the "pinnacle of patient-centered care" and that engagement of the patient when healthcare decisions are to be made as the most important attribute of PCC (Barry, Edge-Levitan, 2012). Others indicate that SDM is an extension of the principles of PFCC and is founded in ethics and law because of its respect of patient autonomy. Bernabeo and Holmboe (2012) indicated that SDM is a

competency that requires the provider to engage a patient. To do this, they must assess patients' preferences and determine any factors that may impede effective decision-making. This is suggestive that SDM is simply an aspect of the patient/provider relationship. Our findings of only one underlying construct for both the FCC and the SDM measures is supportive of the notion that SDM is an attribute of PFCC that leads naturally to the process of shared decision-making.

**Limitations**

This study has multiple limitations. First, all measures are self-reported and thus are subject to recall and social desirability bias. Our findings also cannot be generalized to the general pediatric population or to the adult population. Despite the above limitations, our study included a large nationally represented sample of children with asthma, which increases the generalizability of our findings.

**Conclusions**

Our findings conclude that the measures found in the NS-CSHCN for FCC and SDM are explained by only one construct, which we contend is more indicative of the broader concept of FCC. Our findings also suggest that in the context of this survey, conclusions drawn by measuring of FCC and SDM will yield similar results. However, the reasons for this are not clear. While our findings suggest that SDM is part of FCC, as indicated by the literature, they may also suggest that the survey is not fully measuring SDM, as the four questions highly overlap with those measures of FCC and do not encompass all aspects of the SDM process as Kriston et al (2010) suggested. Our findings further indicate that additional research is needed on measurement tools for

PFCC, that more fully address all aspects of this important care process. Our findings should be validated by additional research that explores the relationship of FCC and SDM, as found in the 2009-2010 NS-CSHCN, and their associations with specific outcomes.

**Table 4.1 Correlations Measures of Family-centered Care and Measures of Shared Decision Making 2009-2010 NS-CSHCN Data Subset States 1-25, N=6,248**

| | 1. Spends enough time | 2. Listens carefully | 3. Sensitive to Needs | 4.Provides needed information | 5. Feel like a partner in healthcare | 6. Discusses treatment options. | 7.Encourage questions | 8.Easy to ask questions |
|---|---|---|---|---|---|---|---|---|
| 2. Listens carefully | 0.51491 | | | | | | | |
| 3.Sensitive to Needs | 0.41671 | 0.56097 | | | | | | |
| 4.Provides needed information | 0.41123 | 0.48901 | 0.46838 | | | | | |
| 5. Feel like a partner in healthcare | 0.42880 | 0.56524 | 0.53062 | 0.55569 | | | | |
| 6. Discusses treatment options. | 0.41085 | 0.50771 | 0.46318 | 0.53966 | 0.58983 | | | |
| 7.Encourage questions | 0.38217 | 0.50076 | 0.46733 | 0.47466 | 0.53339 | 0.57276 | | |
| 8. Makes it easy to ask questions | 0.41601 | 0.58373 | 0.52144 | 0.51111 | 0.59094 | 0.58166 | 0.67413 | |
| 9. respects treatment choices | 0.41206 | 0.56806 | 0.53561 | 0.50982 | 0.59312 | 0.59516 | 0.57869 | 0.66682 |

**Table 4.2 Results of Forced 2-Factor Analysis Eigenvalues2009-2010 NS-CSHCN**

| | **Eigenvalues (States 1-25) (n=6248)** |
|---|---|
| Factor 1 | 4.69237786 |
| Factor 2 | 0.18851656 |
| Factor 3 | 0.06894245 |
| Factor 4 | -0.00960683 |
| Factor 5 | -0.05395974 |
| Factor 6 | -0.07888991 |
| Factor 7 | -0.08710027 |
| Factor 8 | -0.12374987 |
| Factor 9 | -0.1398849 |

**Table 4.3 Results of Forced 2-Factor analysis Factor Patterns 2009-2010 NS-CSHCN Data subset states 1-25 N=6248**

| **Factor Pattern** | | |
|---|---|---|
| | **Factor1** | **Factor2** |
| 1. Spends enough time | 0.57298 | 0.21030 |
| 2. Listens carefully | 0.73913 | 0.18431 |
| 3.Sensitive to Needs | 0.67864 | 0.13827 |
| 4.Provides needed information | 0.67712 | 0.05909 |
| 5. Feel like a partner in healthcare | 0.75939 | 0.03613 |
| 6. Discusses treatment options. | 0.73797 | -0.08421 |
| 7.Encourage questions | 0.73044 | -0.20348 |
| 8. Makes it easy to ask questions | 0.79911 | -0.17372 |
| 9. respects treatment choices | 0.77802 | -0.08793 |
| Eigenvalues | 4.6923 | 0.18851 |
| Variance | 4.6924 | 0.18851 |

**Table 4.4 Results of Forced 2-Factor Analysis, Oblique Rotation Factor Structure 2009-2010 NS-CSHCN Data subset Sates 1-25 N=6248**

| **Factor Structure (Correlations)** | | |
|---|---|---|
| | **Factor1** | **Factor2** |
| 1. Spends enough time | 0.48382 | 0.60926 |
| 2. Listens carefully | 0.65014 | 0.75111 |
| 3.Sensitive to Needs | 0.60619 | 0.67725 |
| 4.Provides needed information | 0.62843 | 0.64417 |
| 5. Feel like a partner in healthcare | 0.71380 | 0.71038 |
| 6. Discusses treatment options. | 0.72937 | 0.64258 |
| 7.Encourage questions | 0.75786 | 0.58794 |
| 8. Makes it easy to ask questions | 0.81449 | 0.66279 |
| 9. respects treatment choices | 0.76869 | 0.67779 |

**Table 4.5 Results from Principal Factor Analysis Eigenvalues 2009-2010 NS-CSHC**N

| | **Eigenvalues (States 1-25) N=6248** | **Eigenvalues (States 26-51) N=6407** |
|---|---|---|
| Factor 1 | 4.69237786 | 4.8643472 |
| Factor 2 | 0.18851656 | 0.2152243 |
| Factor 3 | 0.06894245 | 0.0592241 |
| Factor 4 | -0.00960683 | 0.0130002 |
| Factor 5 | -0.05395974 | -0.038486 |
| Factor 6 | -0.07888991 | -0.081815 |
| Factor 7 | -0.08710027 | -0.090081 |
| Factor 8 | -0.12374987 | -0.131287 |
| Factor 9 | -0.1398849 | -0.134835 |

**Table 4.6 Results from Principal Factor Analysis**
**Factor Patterns 2009-2010 NS-CSHCN**

| Factor Pattern | | |
|---|---|---|
| | **States 1-25 N=6248** | **States 26-51 N=6407** |
| 1. Spends enough time | 0.57298 | 0.56922 |
| 2. Listens carefully | 0.73913 | 0.75743 |
| 3.Sensitive to Needs | 0.67864 | 0.70274 |
| 4.Provides needed information | 0.67712 | 0.69187 |
| 5. Feel like a partner in healthcare | 0.75939 | 0.77594 |
| 6. Discusses treatment options. | 0.73797 | 0.74753 |
| 7.Encourage questions | 0.73044 | 0.73841 |
| 8. Makes it easy to ask questions | 0.79911 | 0.82039 |
| 9. respects treatment choices | 0.77802 | 0.78418 |
| Variance | 4.69237 | 4.8643472 |

**Table 4.7 Cronbach Coefficient Alpha (0.912) with Deleted Variable 2009-2010 NS-CSHCN**

| Deleted Variable | Raw Variables | | Standardized Variables | |
|---|---|---|---|---|
| | Correlation with Total | Alpha | Correlation with Total | Alpha |
| Spends enough time | 0.540252 | 0.912075 | 0.542844 | 0.913548 |
| Listens carefully | 0.726561 | 0.89801 | 0.727362 | 0.900884 |
| Sensitive to needs | 0.669351 | 0.901612 | 0.672186 | 0.904739 |
| Provides information | 0.661389 | 0.902123 | 0.662573 | 0.905405 |
| Feel like a partner | 0.741525 | 0.896684 | 0.743158 | 0.89977 |
| Discusses treatment options | 0.71457 | 0.898207 | 0.713613 | 0.90185 |
| Encourages questions | 0.694525 | 0.900045 | 0.695729 | 0.903101 |
| Easy to ask questions | 0.777047 | 0.894212 | 0.776646 | 0.897391 |
| Respects treatment choices | 0.741744 | 0.8963 | 0.743994 | 0.899711 |

# CHAPTER 5

## THE ASSOCIATIONS OF FAMILY-CENTERED CARE AND SHARED DECISION MAKING WITH RECEIPT OF ALL NEEDED PRESCRIPTION DRUGS AND EMERGENCY DEPARTMENT VISITS IN CHILDREN WITH ASTHMA [2]

[2] Brumbaugh B.L., Probst J.C., Hale N.L., Xirasagar S., Hardin J.W., Wagner P.J. to be submitted *Journal of Asthma*

## Abstract

**Objective:** We examined the association between family-centered care (FCC) and two childhood asthma outcomes; whether the child received of all needed prescription medications and whether the child had no emergency department (ED) visits in the past 12 months. We also examined the association of shared decision making (SDM) and these same asthma outcomes. Our data source was the 2009-2010 National Survey of Children with Special Health Care Needs (NS-CSHCN).

**Methods:** We estimated logistic regression models of FCC and pediatric asthma outcomes on FCC, controlling for predisposing, enabling and need characteristics. We then performed the same analysis utilizing SDM, instead of FCC as the main independent variable of interest.

**Results:** Approximately 64% of children with asthma (n=12,675) reported perceiving their care as family-centered. Receiving FCC is associated with increased odds of getting all needed prescription medications and with having no ED visits in the past 12 months. Children reporting SDM (71%), have increased odds of getting all needed prescription medications and having no ED visit in the past 12 months. Approximately 56% of children with asthma reported receiving both FCC and SDM.

**Conclusions:** All of the components of FCC have important implications in the management and outcomes of childhood asthma. Efforts should continue to implement FCC across the continuum of health care, especially in chronic disease management. In addition, further study of appropriate measures of FCC should be undertaken.

## Introduction

### Patient- and Family- Centered Care

The institute of medicine (IOM) established six aims for quality improvement in health care delivery in their 2001 report, Crossing the Quality Chasm A New Health System for the 21st century. One of these six aims was the provision of care that is patient-centered. The IOM report defined patient-centered care as care that is "respectful of and responsive to individual patient preferences, and values and ensuring that patient values guide all clinical decision (IOM, 2001, pg. 6)." In addition the IOM report said that care should be based on continuous healing relationships, customized based on the patient's values and needs, the patient is the source of control, and knowledge is shared (IOM, 2001). The Institute of Patient- and Family- Centered care linked this definition with the value of the family in healthcare delivery by acknowledging, "that families, however they are defined, are essential to patients' health and well-being and are allies for quality and safety within the health care system (Conway et al, 2006, pg. 5)." Patient- and Family-Centered Care (PFCC) in the pediatric setting is generally referred to as family-centered care. Family-centered care has been affirmed by the American Academy of Pediatrics (AAP) and is considered the standard of care for children. FCC is based upon information sharing, respect, partnership, and care in context with family needs (Kuo, Houtrow, Arango, Kuhlthau, Simmons, 2012).

More recently the patient protection and affordable care act (PPACA) has placed an increased emphasis on shared decision-making (SDM). However, studies have suggested that PFCC is multidimensional and includes SDM along with such things as

the patient-provider relationship. In the 2009-2010 National Survey of Children with Special Health Care a measure of SDM was added to the already established measure of FCC. In our previous study, we found that the key dimensions of both of these measures were very similar and our research determined that they were part of the same construct. This suggested that SDM is a natural extension of FCC. The purposes of this present study are twofold. First, we wish to examine the association of the measures of FCC with specific outcomes. We will also examine the association of the measures of SDM with the same outcomes and compare the two.

**Childhood Asthma**

Asthma care is particularly suitable for the study of FCC and SDM. It is the most common chronic disease among children, affecting over 12% of children (Mattke, Martorell, Sharma, Malveaus, Lurie, 2009). In the United States in 2004, it was estimated that the total cost of treating asthma (adults and children) exceeded $16 billion. Hospital care represented over $11 billion of this cost. While there have been great advances in the treatment of asthma, especially with pharmacotherapy, care still falls short, with 74% of children with moderate to severe asthma not receiving adequate treatment (Mattke et al, 2009). This is a significant public health burden not only on the children's caregivers, but also on schools, employers and the health care system. In many cases, asthma cannot be prevented, but improvement of outcomes is an achievable goal. There are obvious actions that can lead to improved outcomes, such as prescribing anti-inflammatory medications, written treatment plans, and standardized therapy in a medical home setting. Less obvious and often complicated actions include addressing

such barriers as cultural competence and trust issues between provider and caregiver (Akinbami et al, 2009).

In this study, we examine the association of FCC and SDM with the receipt of all needed prescription drugs and emergency department (ED) visits in the past 12 months, among children with asthma. While FCC has been around for a number of years, there are still limited studies that examine this process of care relative to specific outcomes, beyond those of patient and family satisfaction. Additionally, we are not aware of any study that has looked at both FCC and SDM to examine their relationship.

**Methods**

This study utilized the 2009-2010 National Survey of Children with Special Health Care Needs (NS-CSHCN). This survey was primarily sponsored by the United States Department of Health and Human Services (DHHS), Health Resources and Services Administration (HRSA), and Maternal and Child Health Bureau (MCHB). Data were collected between July 7, 2009 and March 2, 2011.

The NS-CSHCN was designed as a cross-sectional telephone survey of US households with at least one resident child aged 0 to 17 years at the time of the survey. It utilized a list-assisted random-digit dial (RDD) sample of landline telephone numbers and this was supplemented with a RDD sample of cell phone numbers. Each telephone number was called and screened for residency and the presence of a child aged 0 to 17 at the time of the call. All children living in the household was screened for special health care needs. If more than one child in the household had special health care needs, one was chosen randomly for the interview. The screener used to identify children with

special health care needs is designed to reflect MCHB definition; "Children with special health care needs are those that have …a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally (Mcpherson et al, 1998)." Respondents for the survey were parent or guardian with knowledge of the health and health of the children in the household. A total of 372,698 children were screened and detailed interviews were completed for 40,242 CSHCN representing all 50 states of the United States.

**Sample**

The sample for both studies were children age 0 to 17 that currently have asthma. To be included, respondents had to answer positively on interview, "Does (subject child) [S.C.] currently have asthma.' A query of the NS-CSHCN, yielded 13,144 children that currently have asthma. Our final data set included 12,675 children that currently have asthma. This was after removal of cases where there was a refusal to answer a question or the care giver did not know the answer.

**Conceptual Framework**

The overall conceptual framework for this study is Donabedian's structure/process/outcomes framework for assessing health care quality. In Donabedian's framework, structure refers to the setting in which care is received. That framework includes such things as organizational structure, culture, and information technology (Edwardson, 2007). Structure can also include such things as qualifications of care providers, as well as patient characteristics (Elverson, Samra, 2012) Process refers to how

and what care is delivered and how it is received and finally outcomes refers to health status, because of the care that is received. Outcomes are not only those technical outcomes like prevention of complications, but also patient satisfaction or a patient's perceived quality of care that is based on interpersonal relationships between the provide and the patient. Donabedian also asserted that structure, process and outcome are not independent of one another (Donabedian, 1988).

In addition to Donabedian, the conceptual framework is also based upon Andersen's (1995) Behavioral Health Model. This model indicates that health care utilization is dependent upon multiple factors that are described as predisposing characteristics, enabling resources and perceived and/or actual need. The factors are influenced by the system of care available (Andersen, 1995, 2008).

Finally, the conceptual framework is also based upon the biopsychosocial model of health care. It is a model that considers all the biological, social and psychological factors that influence health. Figure 5.1 provides the Conceptual Model.

## Independent Variables

The independent variables for this study were the receipt of family-centered care and the experience of SDM. Family centered care was considered present if parents answered (Coker, Rodriguez, Flores, 2010; Drummond, Looman, Phillips, 2011; Ngui, Flores, 2006) "always" or "usually" to the following five questions:

1. [During the past 12 months / since [his/her] birth], how often did [S.C.]'s doctors and other health care providers spend enough time with [him/her]?

2. [During the past 12 months / since [his/her] birth], how often did [S.C.]'s doctors and other health care providers listen carefully to you?
3. When [S.C.] is seen by doctors or other health care providers, how often are they sensitive to your family's values and customs?
4. During the past 12 months / since [his/her] birth], how often did you get specific information you needed from [S.C.]'s doctors or other health care providers?
5. During the past 12 months / since [his/her] birth], how often did [S.C.]'s doctors and other health care providers help you feel like a partner in [his/her] care?

These five questions were derived partly from the Consumer Assessment of Healthcare Providers and Systems (CAHPS) survey and partly from the American Academy of Pediatricians in the framework of the Medical Home Model (Dissertation, FCC autism,). These five questions have also be found to be quite reliable with an alpha of 0.84 (Drummond, Looman, Phillips, 2011).

SDM measures were included as a separate independent variable. The questions relative to shared decision-making are as follows:

1. "[During the past 12 months / since [his/her] birth], how often did [S.C.]'s doctors or other health care providers discuss with you the range of options to consider for [his/her] health care or treatment?"
2. "[During the past 12 months / since [his/her] birth], how often did [S.C.]'s doctors or other health care providers encourage you to ask questions or raise concerns?"

3. "[During the past 12 months / since [his/her] birth], how often did [S.C.]'s doctors or other health care providers make it easy for you to ask questions or raise concerns?"
4. "[During the past 12 months / since [his/her] birth], how often did [S.C.]'s doctors or other health care providers consider and respect what health care and treatment choices you thought would work best for [S.C.]?"

For each question an answer of "always" or "usually" indicated that parents perceived themselves as sharing in decision making with their child's health care providers, while responses of "sometimes" or "never" will indicate that parents do not perceive themselves as sharing in decision making with their child's health care providers. These four measures together provide for a composite variable of shared decision-making. Answers of "always" or "usually" to all four questions demonstrate that parents perceive themselves as sharing in decision making.

**Dependent Variables**

The primary outcome measures were the receipt of all needed prescription drugs in the past year and no ED visits in the past year. The receipt of all needed prescription drugs was measured by the answer to the following question:

"Did [S.C.] receive all the prescription medication that [he/she] needed?"

The receipt of all needed prescription drugs was coded as dichotomous.

ED visits were measured by the answer to the following question:

"During the past 12 months/ since [his/her] birth, how many times did [S.C.] visit a hospital emergency room?"

ED visits were coded a two level variable: 0 and 1 or more visits.

**Other Variables**

The predisposing characteristics that were held constant were the child's age, sex, race/ethnicity, highest education level of parent or guardian, and family structure. Age was coded as a three level categorical variable: 0 to 5 years, 6 to 11 years and 12 to 17 years (Diedhiou et al, 2010). The highest education level was coded as a three level categorical variable: less than high school, high school graduate, and more than high school. Family structure was coded as a three level categorical variable: Two parent family, single mother with no father present, and other. Race/ethnicity was coded as a three level categorical variable: White, Black and other.

The enabling characteristics that were held constant were income and insurance status. Income as measured by percent of federal poverty level (FPL) was coded as a three level categorical variable: 0% to 200% of FPL, 201% to 400% FPL, and greater than 400% of FPL. Insurance status was coded as a four level categorical variable: Private insurance, public insurance, other and uninsured.

The need characteristic that was held constant was breathing difficulties. Breathing difficulty was measured by the answer to the following question:

> "Would you say [he//she] experiences a lot, a little or no difficulty with breathing or other respiratory problems, such as wheezing or shortness of breath?"

Breathing Difficulty was coded as a three level categorical variable: a lot of difficulty, a little difficulty, and no difficulty.

## Analysis

Bi-variate analysis was used to compare variables. Chi square tests were used to determine independence. Multivariable logistic regression models were run with each of the outcomes, ED visits and receipt of all needed drugs, as the dependent variables. Receipt of FCC and SDM were the primary independent variables for both outcomes. Covariates (predisposing, enabling and need) were studied for confounding and interaction among covariates and outcomes. Our modeling strategy was first to examine the unadjusted model for each outcome. Our second model was adjusting for all variables and finally the third models were adjusting only for variables that were significant in the complete model. Our analyses controlled for the complex sample design of the NS-CSHCN. The University of South Carolina Institutional Review Board approved our research. All analysis was conducted with SAS v. 9.4.

## Results

### *Characteristics of the study population*

Characteristics of children with asthma ($n$ = 12,675) from the 2009-2010 NS-CSHCN are shown in Table 5.1. Approximately 77% of the children were aged between six and 17 years, almost half were female, and were overwhelmingly white at 74%. Forty nine percent of the children had private health insurance and over 96% had some form of insurance. Over two thirds lived in households with incomes greater than 200% of the poverty level. Nearly 80% of the children lived in families that were educated beyond high school and 62% lived in two parent households. More than 91% report some breathing difficulty.

Approximately 64% of parents reported perceiving their care as family-centered and 71% experienced SDM. The demographic characteristics of the child were not associated with FCC or SDM, however the clinical characteristics were. The higher the need (breathing difficulties) for care, the less likely the parent would report FCC or SDM. There were two enabling characteristics associated with the receipt of FCC, having private health insurance and living in a two-parent household. Table 5.1 provides the characteristics of children with asthma and by receipt of FCC and SDM.

***Bivariate Relationships***

Nearly 97% of children with asthma were reported to receive all needed prescription medication. Children who were described as non-white and non-black were more likely not to have received needed prescription medications than white or black children, as were the uninsured. Also living in a family where there was a mother, but no father present were more likely to report not receiving all needed prescriptions drugs. Nearly 98% of children reporting FCC received all of their needed prescription medications, while 94% not receiving FCC reported the same. There were very similar findings for children experiencing SDM.

More than half (51%) of children with asthma were reported to have no emergency department visits in the last 12 months. Children whose parents report receiving FCC were less likely to have visited an ED than those who reported they did not receive such care (45.47 vs. 54.51 respectively). A similar relationship was present for SDM. Other factors associated with making ED visits included age, sex, insurance status, family structure and need. Approximately 64% of children aged 0-5 years

reported at least one ED visit in the past year, verses children age 12 to 17(43%). Sixty one percent of children with public health insurance reported at least one ED visit, while only 38% of those with private health insurance reported a visit. Single mothers with no father present were more likely to report an ED visit, than other family structures. Children with a lot of breathing difficulties were also less likely to have no ED visits than those who report only a little difficulty or no breathing difficulty. See Table 5.2 for bivariate relationships.

### *Adjusted Models*

#### *Receipt of Prescription Medications*

Children reported to have received FCC had 3.62 higher odds of getting all needed prescription medications (Table 5.3). After adjusting for predisposing, enabling, and need variables, children reported to receive FCC had over three times the odds of getting all needed prescription medications. Among other covariates associated with medication receipt in bivariate analysis, only insurance status was significant in adjusted models. A final model was run that included only insurance status, which was significant and again children that reported receiving FCC had nearly three times the odds of receiving all needed prescription medication. Only one other variable was more significant in predicting receipt of all needed drugs and that was insurance status. Children with any type of health insurance were significantly more likely to report having received all prescription drugs than those who were uninsured. The adjusted associations between receiving all needed prescription medications and FCC are presented in Table 5.3.

Children who reported SDM had a 3.88 higher odds of receiving all needed prescription medications than those who did not report SDM (Table 5.4). After adjusting for predisposing, enabling, and need variables, children who reported receiving SDM had 3.41 higher odds of receiving all needed prescription drugs. Insurance status remained significantly associated with the receipt of all needed prescription medications so a final model was run controlling for this variable. Children receiving SDM had 3.47 higher odds of receiving all needed prescription drugs and insurance remained a significant predictor in this final model. The adjusted associations between receiving all needed prescription medications and SDM are presented in Table 5.4.

Children who reported FCC while controlling for SDM had a 2.32 higher odds of receiving all needed prescription medication than those who did not report FCC (Table 5.5). Children who reported SDM, while controlling for FCC had a 2.59 higher odds of receiving all needed prescriptions medication than those who did not report SDM. After adjusting for predisposing, enabling and need variables, both FCC and SDM remained a significant predictor of receiving all needed prescription medication. Insurance status also remained a significant predictor of receiving all needed prescription drugs. A final model was controlling for FCC, SDM and insurance status. In this model both SDM and FCC were significant predictors of receiving all needed prescription drugs, as was insurance status. The adjusted associations between receiving all needed prescription medications and FCC and SDM are presented in Table 5.5.

*Emergency Department*

Children that report receiving FCC had 1.44 higher odds of having no ED visits in the past 12 months (Table 5.6). After adjusting for predisposing, enabling, need variables and receipt of all needed drugs , children that reported receiving FCC had 1.31 higher odds of having no ED visits in the past 12 months. The other variables that remained significant were child's age and insurance status. The third model with controlling for these two variables again found that children reporting FCC had 1.06 higher odds of having no ED visits in the past year. Age and insurance status remained significant predictors of ED visits. Younger children were half as likely to report no ED visits as older children. Children with private health insurance were more likely to report no ED visits, compared to those who are uninsured. However, children who report having public health insurance are over half as likely to report no ED visits in the past year as those that are uninsured. The adjusted associations between ED visits and FCC are presented in Table 5.6.

Children experiencing SDM had 1.42 higher odds of not visiting the ED in the past 12 months (Table 5.7). After adjusting for predisposing, enabling, need variables, and receipt of all needed prescription drugs, children that reported receiving SDM had 1.18 higher odds of having no ED visits in the past 12 months. The other variables that remained significant were child's age, family structure and report of breathing difficulty. The third model with controlling for these four variables again found that children reporting SDM had 1.26 higher odds of having no ED visits in the past year. Age, insurance status, family structure and report of breathing difficulty remained significant

predictors of ED visits. The adjusted associations between ED visits and SDM are presented in Table 5.7.

Children receiving FCC, while controlling for SDM had 1.31 higher odds of not visiting the ED in the past 12 months (Table 5.8). Children experience SDM, while controlling for FCC had a 1.25 higher odds of not visiting the ED in the past 12 months. After adjusting for predisposing, enabling and need variables, FCC remained a significant predictor of not visiting the ED in the past 12 months, however, SDM was not a significant predictor. The other variables that remained significant were child's age, family structure, insurance status and report of breathing difficulty. The third model with controlling for these four variables again and including FCC and SDM found that SDM was a significant predictor of no ED visits in the past year, but FCC was no longer significant. Age, insurance status, family structure and report of breathing difficulty remained significant predictors of ED visits. The adjusted associations between ED visits, FCC and SDM are presented in Table 5.8.

**Discussion**

Our study indicates the importance of family centered care in childhood asthma outcomes. Our findings are supportive of the National Heart and Lung Institute's recommendation that a partnership between the patient and provider be both established and maintained (EPRP-3, 2007). Our research results are consistent with the literature that FCC and its components provide for better outcomes in asthma care. FCC and SDM were both significantly associated with the receipt of all needed prescriptions drugs. While not directly measured in our study it can be asserted that prescribing practices and

drug or treatment adherence is related to receipt of needed prescription drugs. Multiple studies suggest that FCC supports medication prescribing and adherence. Halterman et al (2002) demonstrated that the patient provider relationship was associated with an underestimation of asthma severity and subsequently under prescribing of maintenance medication. In addition, family-centered communication at the time of drug prescribing is more likely to lead to drug adherence (Con et al, 2005). Another study demonstrated this same relationship. Drug adherence was enhanced when there was good communication between the patient and the provider (Apter, Reisine, Affleck, Barrows, ZuWallack, 2998).

FCC and SDM as measured in this survey were both significantly associated with no ED visits in the past 12 months. The literature has demonstrated that the aspects of partnerships and information sharing between providers and patients have been shown to reduce ED visits in Asthma patients. When physicians were regarded as thorough there was a reduction in ED visits (Clark et al, 2008). Similarly, Carbana et al (2006) found that in children with asthma receiving care from physicians that had completed a continuing medical education program to improve asthma communication skills, had fewer ED visits. Diedhiou et al (2010) found a relationship between ED use in children with asthma and FCC and concluded that increasing family competence in the care of their child and providing care that meets the needs of the family will decrease ED use.

There is very limited research that has examined SDM and none that looked at the receipt of prescription drugs and ED visits among children with asthma. Smalley et al (2013) used the measure to examine the prevalence of SDM among families of children with special health care needs. Their findings included high prevalence of SDM as our

study did. They too, found a significant association between FCC and SDM. However, there is evidence in the literature that the patient/provider partnership or treatment alliance is necessary in achieving shared decision-making (Gavin, Wamboldt, Sorokin, Levy, Wamboldt, 1999).

Our models that included both SDM and FCC were not significantly different from our individual models, although FCC was no longer a significant predictor of not having ED visits in the past 12 months, when the model was adjusted for SDM. However, this outcome was only slightly different from our model that did not adjust for SDM. The differences in the models more than likely can be explained by our previous work that demonstrated that FCC and SDM share one underlying construct. This also would explain the limited differences in outcomes relative to SDM and FCC separately. These findings would imply that we should develop a new metric of FCC that includes questions concerning SDM. Having two measures that have only one underlying construct is over burdensome in practice and most likely does not provide for additional information in results, as was demonstrated in our study where there was only limited differences in the outcomes relative to FCC and SDM.

**Limitations**

Limitations of the present study include the measurement of FCC and SDM. We utilized an "on every" rating approach. For instance, a provider could meet every aspect of FCC except "spending enough time" and care would not be considered family-centered. Additionally, the data are cross-sectional and does not allow for summation of causal or temporal relationships. This data are also self-reported, without the ability to

examine medical records. Self-reported data are subject to recall and social desirability bias. In addition, our findings cannot be generalized to the general pediatric population or to the adult population. However, we did utilize a large data set, which does allow for more generalizability.

**Conclusions**

All of the components of FCC have important implications in the management and outcomes of childhood asthma. Efforts should continue to implement this important process of care across the continuum of health care, especially in chronic disease management. In addition, further study of appropriate measures of FCC should be undertaken. It is important to develop appropriate measures that examine all aspects of this important process of care, including SDM. However, it is also important that we utilize a measure that is not over burdensome in practice, and provides adequate information.

**Table 5.1 Characteristics of Children with Asthma (n=12,675) Total and by receipt of Family Centered Care and Shared Decision Making 2009-2010 NS-CSHCN**

| Weighted Percentages (standard error) | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | | | FCC | | | SDM | | |
| **Covariate** | **Children with Asthma (%)** | | **Yes** | | ***p*** | **Yes** | | ***p*** |
| **Percent Receiving** | 100.00 | | 64.24 | | | 71.49 | | |
| **Predisposing Charact.** | | | | | | | | |
| **Age (years)** | | | | | 0.6346 | | | 0.0629 |
| 0 - 5 | 22.37 | 0.68 | 63.05 | 0.54 | | 68.51 | 0.57 | |
| 6 - 11 | 40.43 | 0.78 | 65.04 | 0.68 | | 71.60 | 0.71 | |
| 12 - 17 | 37.19 | 0.77 | 64.08 | 0.65 | | 73.17 | 0.71 | |
| **Sex** | | | | | 0.7364 | | | 0.3469 |
| Female | 49.37 | 0.8 | 63.96 | 0.72 | | 72.19 | 0.76 | |
| Male | | | | | | | 0.76 | |
| | | | | | | 70.81 | | |
| **Race** | | | | | 0.0936 | | | 0.7402 |
| White | 74.3 | 0.72 | 64.61 | 0.82 | | 71.10 | 0.82 | |
| Black | 9.4 | 0.47 | 66.46 | 0.39 | | 72.52 | 0.41 | |
| Other | 16.3 | 0.61 | 60.28 | 0.44 | | 72.35 | 0.53 | |
| **Enabling Charact.** | | | | | | | | |
| **Insurance Status** | | | | | <.0001 | | | <.0001 |
| Private | 49.14 | 0.8 | 72.83 | 0.72 | | 77.51 | 0.74 | |
| Public | 37.31 | 0.8 | 56.08 | 0.69 | | 66.26 | 0.74 | |
| Other | 9.67 | 0.47 | 61.38 | 0.36 | | 65.85 | 0.37 | |
| Uninsured | 3.88 | 0.41 | 41.01 | 0.18 | | 59.70 | 0.35 | |
| **Income (%PL)** | | | | | 0.6547 | | | 0.7676 |
| 0 - 200 | 25.04 | 0.58 | 65.91 | 0.68 | | 70.76 | 0.71 | |
| 201 - 400 | 26.74 | 0.61 | 63.75 | 0.69 | | 70.75 | 0.74 | |
| > 400 | 30.06 | 0.63 | 63.99 | 0.72 | | 72.46 | 0.77 | |
| Missing | 18.16 | 0.53 | 63.07 | 0.48 | | 71.99 | 0.56 | |
| **Highest Education** | | | | | 0.631 | | | 0.4031 |
| < high school | 4.48 | 0.32 | 66.14 | 0.25 | | 71.58 | 0.25 | |
| HS Grad. | 15.53 | 0.59 | 65.94 | 0.45 | | 73.95 | 0.52 | |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| >high school | 79.99 | 0.64 | 64.06 | 0.82 | | 71.15 | 0.81 | |
| **Family Structure** | | | | | <.0001 | | | <.0001 |
| 2 parent household | 62.26 | 0.8 | 69.71 | 0.78 | | 74.56 | 0.80 | |
| Single Mother | 30.83 | 0.78 | 54.76 | 0.61 | | 67.15 | 0.70 | |
| Other | 6.91 | 0.42 | 58.02 | 0.32 | | 65.51 | 0.34 | |
| **Need Charact. Breathing difficulties** | | | | | <.0001 | | | 0.0029 |
| a lot | 22.67 | 0.69 | 57.91 | 0.53 | | 66.60 | 0.59 | |
| a little | 68.77 | 0.76 | 65.51 | 0.78 | | 72.82 | 0.80 | |
| None | 8.56 | 0.48 | 70.81 | 0.41 | | 73.79 | 0.40 | |

**Table 5.2 Characteristics of Children with Asthma (n=12,675) By receipt of prescription drugs and ED visits 2009-2010 NS-CSHCN**

| | Weighted Percentages (standard error) | | | | | |
|---|---|---|---|---|---|---|
| **Covariate** | **Received all prescription drugs** | | *p* value | **1+ ED visits** | | *p* value |
| **Total** | 96.68 | | | 48.69 | | |
| **FCC** | | | <.0001 | | | <.0001 |
| Yes | 98.22 | 0.81 | | 45.47 | 0.72 | |
| No | 93.84 | 0.80 | | 54.51 | 0.67 | |
| **SDM** | | | <.0001 | | | <.0001 |
| Yes | 98.13 | 0.76 | | 46.20 | 0.75 | |
| No | 93.10 | 0.73 | | 54.98 | 0.61 | |
| **Predisposing Characteristics** | | | | | | |
| **Age (years)** | | | 0.0637 | | | <.0001 |
| 0 - 5 | 98.13 | 0.69 | | 63.51 | 0.59 | |
| 6 - 11 | 96.38 | 0.79 | | 46.04 | 0.62 | |
| 12 - 17 | 96.14 | 0.78 | | 42.67 | 0.58 | |
| **Sex** | | | 0.7183 | | | 0.0322 |
| Female | 96.56 | 0.82 | | 46.97 | 0.67 | |
| Male | 96.80 | 0.82 | | 50.38 | 0.72 | |
| **Race** | | | 0.0174 | | | 0.4784 |
| White | 96.98 | 0.76 | | 49.30 | 0.80 | |
| Black | 97.11 | 0.49 | | 45.95 | 0.33 | |
| Other | 94.35 | 0.60 | | 49.49 | 0.47 | |
| **Enabling Characteristics** | | | | | | |
| **Insurance Status** | | | <.0001 | | | <.0001 |
| Private | 98.27 | 0.82 | | 38.28 | 0.58 | |
| Public | 95.71 | 0.81 | | 61.18 | 0.72 | |
| Other | 98.02 | 0.47 | | 55.60 | 0.36 | |
| Uninsured | 81.64 | 0.41 | | 43.10 | 0.25 | |
| **Income(%PL)** | | | 0.6971 | | | 0.2643 |
| 0 - 200% | 96.47 | 0.83 | | 46.90 | 0.62 | |
| 201% - 400% | 96.18 | 0.84 | | 50.64 | 0.71 | |
| > 400% | 97.16 | 0.85 | | 49.48 | 0.68 | |
| Missing | 96.93 | 0.63 | | 46.99 | 0.42 | |
| **Highest Education** | | | 0.1265 | | | 0.2358 |
| < high school | 96.66 | 0.33 | | 44.77 | 0.21 | |
| HS Grad. | 97.99 | 0.60 | | 46.43 | 0.42 | |
| > high school | 96.44 | 0.71 | | 49.31 | 0.81 | |

| | | | | | | |
|---|---|---|---|---|---|---|
| **Family Structure** | | | 0.0024 | | | <.0001 |
| 2 parent household | 97.21 | 0.82 | | 44.13 | 0.72 | |
| Single Mother | 95.17 | 0.78 | | 57.54 | 0.64 | |
| Other | 97.87 | 0.43 | | 51.30 | 0.29 | |
| **Need Characteristics** | | | | | | |
| **Breathing difficulties** | | | 0.0772 | | | <.0001 |
| a lot | 95.31 | 0.71 | | 68.48 | 0.61 | |
| a little | 97.12 | 0.79 | | 43.51 | 0.73 | |
| None | 96.89 | 0.45 | | 37.83 | 0.29 | |

**Table 5.3 Logistic Regression Models of All Drugs Received and SDM; 2009-2010 NS-CSHCN**

| All Drugs Received | Model 1 OR (CL) | *p* | Model 1 OR (CL) | *p* | Model 2 OR (CL) | *p* |
|---|---|---|---|---|---|---|
| **SDM** | 3.88 (2.51 – 5.99) | <.0001 | 3.41 (2.07 – 5.63) | 0.0002 | 3.47 (2.19 – 5.49) | <.0001 |
| **Age** | | | | 0.0562 | | |
| 0-5v 12-17 | | | 2.29 (1.12 – 4.67) | | | |
| 6-11v 12-17 | | | 1.02 (0.62 – 1.69) | | | |
| **Sex** | | | | 0.3645 | | |
| M v F | | | 1.23 (0.79 - 1.93) | | | |
| **Race** | | | | 0.3480 | | |
| White v other | | | 1.60 (0.85 – 3.02) | | | |
| Black v other | | | 1.55 (0.70 – 3.46) | | | |
| **Insurance Status** | | | | <.0001 | | <.0001 |
| private v uninsured | | | 9.16 (4.37 – 19.21) | | 10.55 (5.43 – 20.52) | |
| public v uninsured | | | 5.39 (2.75 – 10.58) | | 4.88 (2.57 – 9.25) | |
| other v uninsured | | | 10.26 (3.96 – 26.57) | | 10.85 (4.39 – 26.82) | |
| **Income (%PL)** | | | | 0.6720 | | |
| 0-200 v >400 | | | 0.78 (0.43 - 1.42) | | | |

| | | | |
|---|---|---|---|
| 201-400 v >400 | 0.68 | (0.37 - 1.26) | |
| **Education** | | | 0.1662 |
| No HS v college | 1.13 | (0.41 –3.11) | |
| HS grad vs some college | 1.80 | (0.98 – 3.29) | |
| **Family Structure** | | | 0.1297 |
| 2 parent v Other | 0.60 | (0.32 – 1.11) | |
| Single parent v other | 0.51 | (0.26 – 0.99) | |
| **Breathing Difficulty** | | | 0.3017 |
| a lot v none | 0.77 | (0.29 – 2.05) | |
| a little v none | 1.13 | (0.41 – 3.15) | |

**Table 5.4 Logistic Regression Models of All Drugs Received and FCC; 2009-2010 NS-CSHCN**

| All Drugs Received | Model 1 OR (CL) | *p* | Model 2 OR (CL) | *p* | Model 3 OR (CL) | *p* |
|---|---|---|---|---|---|---|
| **Family-Centered Care** | 3.62 (2.33 -5.63) | <.0001 | 3.09 (1.80 – 5.29) | <.0001 | 2.90 (1.82 – 4.62) | <.0001 |
| **Age** | | | | 0.0774 | | |
| 0-5 v 12-17 | | | 2.19 (1.07 - 4.50) | | | |
| 6-11v 12-17 | | | 1.02 (0.63 - 1.67) | | | |
| **Sex** | | | | 0.3317 | | |
| males v females | | | 1.25 (0.80 - 1.95) | | | |
| **Race** | | | | 0.4263 | | |
| White vs other | | | 1.53 (0.81 – 2.88) | | | |
| Black vs other | | | 1.44 (0.63 - 3.26) | | | |
| **Insurance Status** | | | | <.0001 | | <.0001 |
| private v uninsured | | | 8.53 (4.24 - 17.18) | | 9.13 (4.71 – 17.69) | |
| public vs uninsured | | | 4.94 (2.59 – 9.44) | | 4.32 (2.30 – 8.11) | |
| other vs uninsured | | | 9.21 (3.59- 23.62) | | 9.15 (3.69 – 22.68) | |
| **Income (%PL)[3]** | | | | 0.6074 | | |
| 0-200 V >400 | | | 0.75 (0.42 - 1.35) | | | |
| 201-400 v >400 | | | 0.68 (0.37 - 1.23) | | | |
| **Education** | | | | 0.1242 | | |
| No HS v college | | | 1.11 (0.40 – 3.07) | | | |
| HS grad v some college | | | 1.94 (1.02 – 3.65) | | | |
| **Family Structure** | | | | 0.1450 | | |
| 2 parent v Other | | | 0.58 (0.31 - 1.09) | | | |
| Single parent v other | | | 0.52 (0.27 – 1.02) | | | |

| | | | |
|---|---|---|---|
| **Breathing Difficulty** | | | 0.4823 |
| a lot v none | 0.88 | (0.33 – 2.36) | |
| a little v none | 1.20 | (0.43 – 3.29) | |



[3] Used missing income data in all analyses, however, it is not shown in the tables.

**Table 5.5 Logistic Regression Models of All Drugs Received and FCC + SDM; 2009-2010 NS-CSHCN**

| All Drugs Received | Model 1 OR (CL) | *p* | Model 2 OR (CL) | *p* | Model 3 OR (CL) | *p* |
|---|---|---|---|---|---|---|
| **FCC** | 2.32 (1.58 -3.57) | <.0001 | 2.04 (1.21 – 3.42) | 0.0073 | 2.88 (1.22 – 2.91) | 0.0045 |
| **SDM** | 2.59 (1.70 – 3.96) | <.0001 | 2.46 (1.54 – 3.93) | 0.0002 | 2.61 (1.78 – 4.00) | <.0001 |
| **Age** | | | | 0.0551 | | |
| 0-5 v 12-17 | | | 2.29 (1.13 - 4.65) | | | |
| 6-11v 12-17 | | | 1.04 (0.63 - 1.71) | | | |
| **Sex** | | | | 0.3333 | | |
| males v females | | | 1.25 (0.80 - 1.96) | | | |
| **Race** | | | | 0.4036 | | |
| White vs other | | | 1.55 (0.81 – 2.95) | | | |
| Black vs other | | | 1.49 (0.66 - 3.37) | | | |
| **Insurance Status** | | | | <.0001 | | <.0001 |
| private v uninsured | | | 8.16 (2.62 – 16.73) | | 9.21 (4.80 – 17.67) | |
| public vs uninsured | | | 5.04 (2.62 – 9.69) | | 4.58 (2.46 – 8.54) | |
| other vs uninsured | | | 9.44 (3.68- 24.21) | | 9.97 (4.06 – 24.50) | |
| **Income (%PL)** | | | | 0.6657 | | |
| 0-200 V >400 | | | 0.77 (0.42 - 1.39) | | | |
| 201-400 v >400 | | | 0.68 (0.37 - 1.26) | | | |
| **Education** | | | | 0.1525 | | |
| No HS v college | | | 1.11 (0.40 – 3.07) | | | |
| HS grad v some college | | | 1.84 (0.99 – 3.41) | | | |
| **Family Structure** | | | | 0.1327 | | |
| 2 parent v Other | | | 0.58 (0.30 - 1.08) | | | |
| Single parent v other | | | 0.52 (0.26 – 1.01) | | | |

| | | | |
|---|---|---|---|
| **Breathing Difficulty** | | | 0.3966 |
| a lot v none | 0.85 | (0.32 – 2.29) | |
| a little v none | 1.20 | (0.43 – 3.34) | |

**Table 5.6 Logistic Regression Models of Emergency Room visits=0 and FCC 2009-2010 NS-CSHCN**

| ED Visits = 0 | Model 1 OR (CL) | *p* | Model 2 OR (CL)2 | *p* | Model 3 OR (CL) | *p* |
|---|---|---|---|---|---|---|
| **FCC** | 1.44 (1.25 - 1.65) | <.0001 | 1.31 (1.12 - 1.53) | 0.0007 | 1.06 (1.06 -1.41) | 0.0064 |
| **Drugs received=Yes** | | | 1.29 (0.77 – 2.16) | 0.3422 | | |
| **Age** | | | | <.0001 | | <.0001 |
| 0-5 v 12-17 | | | 0.49 (0.40 - 0.60) | | 0.48 (0.40 - 0.57) | |
| 6-11 v 12-17 | | | 1.02 (0.87 - 1.19) | | 0.92 (0.79 - 1.06) | |
| **Sex** | | | | 0.2526 | | |
| M v F | | | 0.92 (0.80 - 1.06) | | | |
| **Race** | | | | 0.4325 | | |
| White v other | | | 0.91 (0.75 - 1.10) | | | |
| Black v other | | | 1.03 (0.77 - 1.39) | | | |
| **Insurance Status** | | | | <.0001 | | <.0001 |
| private v uninsured | | | 0.98 (0.62 - 1.56) | | 1.06 (0.70 - 1.62) | |
| public v uninsured | | | 0.48 (0.30 - 0.78) | | 0.53 (0.35 - 0.82) | |
| other v uninsured | | | 0.64 (0.39 - 1.07) | | 0.65 (0.41 - 1.03) | |
| **Income(%PL)** | | | | 0.8038 | | |
| 0-200 v >400 | | | 1.07 (0.87 - 1.32) | | | |
| 201-400 v >400 | | | 1.01 (0.84 - 1.21) | | | |

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|---|---|---|---|---|---|---|
| **Education** | | | 0.3277 | | | |
| No HS v college | 1.12 | (0.80 - 1.55) | | | | |
| HS grad v some college | 1.17 | (0.95 – 1.44) | | | | |
| **Family Structure** | | | <.0206 | | | <.0161 |
| 2 parent v Other | 1.00 | (0.74 – 1.36) | | 1.02 | (0.77 - 1.35) | |
| Single parent v other | 0.79 | (0.58 – 1.08) | | 0.81 | (0.61 – 1.08) | |
| **Breathing Difficulty** | | | <.0001 | | | <.0001 |
| a lot v none | 0.37 | (0.27 - 0.51) | | 0.33 | (0.25 - 0.44) | |
| a little v none | 0.85 | (0.64 -1.12) | | 0.77 | (0.59 - 1.00) | |

**Table 5.7 Logistic Regression Models ED Visits = 0 and SDM, 2009-2010 NS-CSHCN**

| ED Visits = 0 | Model 1 OR (CL) | *p* | Model 2 OR (CL) | *p* | Model 3 OR (CL) | *p* |
|---|---|---|---|---|---|---|
| **SDM** | 1.42 (1.24 - 1.64) | <.0001 | 1.18 (0.99 - 1.41) | 0.0333 | 1.26 (1.09 – 1.46) | 0.0024 |
| **Drugs received=Yes** | | | 1.19 (0.68 – 2.08) | 0.3088 | | |
| **Age** | | | | <.0001 | | <.0001 |
| 0-5 v 12-17 | | | 0.50 (0.41 - 0.62) | | 0.48 (0.40 – 0.58) | |
| 6-11 v 12-17 | | | 1.03 (0.86 - 1.22) | | 0.92 (0.80 – 1.07) | |
| **Sex** | | | | 0.2597 | | |
| M v F | | | 0.89 (0.76 - 1.04) | | | |
| **Race** | | | | 0.4648 | | |
| White vs other | | | 0.91 (0.74 - 1.13) | | | |
| Black vs other | | | 1.02 (0.74 - 1.41) | | | |
| **Insurance Status** | | | | <.0001 | | <.0001 |
| private vs uninsured | | | 1.19 (0.73 - 1.95) | | 1.08 (0.71 – 1.64) | |
| public vs uninsured | | | 0.57 (0.35 - 0.94) | | 0.54 (0.35 – 0.82) | |
| other vs uninsured | | | 0.80 (0.47 - 1.35) | | 0.67 (0.42 – 1.05) | |
| **Income** | | | | 0.7810 | | |
| 0-200 V >400 | | | 1.08 (0.88 - 1.33) | | | |
| 201-400 v >400 | | | 1.01 (0.84 - 1.21) | | | |
| **Education** | | | | 0.3373 | | |
| No HS v college | | | 1.13 (0.76 - 1.66) | | | |
| HS grad v some college | | | 1.11 (0.88 - 1.40) | | | |
| **Family Structure** | | | | 0.0124 | | 0.0110 |
| 2 parent vs Other | | | 1.06 (0.77 - 1.48) | | 1.02 (0.78 – 1.35) | |
| Single parent vs other | | | 0.81 (0.58 – 1.14) | | 0.80 (0.60 – 1.07) | |

| | | | | | | |
|---|---|---|---|---|---|---|
| **Breathing Difficulty** | | | <.0001 | | | <.0001 |
| a lot v none | 0.34 | (0.24 - 0.48) | | 0.33 | (0.25 – 0.44) | |
| a little v none | 0.78 | (0.58 -1.05) | | 0.76 | (0.59 – 0.99) | |

**Table 5.8 Logistic Regression Models ED Visits = 0 and FCC + SDM, 2009-2010 NS-CSHCN**

| ED Visits = 0 | Model 1 OR (CL) | *p* | Model 2 OR (CL)2 | *p* | Model 3 OR (CL) | *p* |
|---|---|---|---|---|---|---|
| **FCC** | 1.31 (1.12 - 1.53) | 0.0009 | 1.27 (1.07 - 1.52) | 0.0066 | 1.14 (0.97 -1.33) | 0.1231 |
| **SDM** | 1.25 (1.06 – 1.47) | 0.0069 | 1.07 (0.89 – 1.28) | 0.4727 | 1.19 (1.00 – 1.41) | 0.0434 |
| **Drugs received=Yes** | | | 1.27 (0.76 – 2.14) | 0.3625 | | |
| **Age** | | | | <.0001 | | <.0001 |
| 0-5 v 12-17 | | | 0.49 (0.41 - 0.60) | | 0.48 (0.40 - 0.57) | |
| 6-11 v 12-17 | | | 1.02 (0.87 - 1.20) | | 0.92 (0.79 - 1.07) | |
| **Sex** | | | | 0.2591 | | |
| M v F | | | 0.92 (0.80 - 1.06) | | | |
| **Race** | | | | 0.4396 | | |
| White v other | | | 0.91 (0.75 - 1.10) | | | |
| Black v other | | | 1.03 (0.77 - 1.39) | | | |
| **Insurance Status** | | | | <.0001 | | <.0001 |
| private v uninsured | | | 0.98 (0.62 - 1.56) | | 1.05 (0.69 - 1.60) | |
| public v uninsured | | | 0.48 (0.30 - 0.77) | | 0.53 (0.35 - 0.81) | |
| other v uninsured | | | 0.65 (0.39 - 1.07) | | 0.65 (0.42 - 1.02) | |
| **Income(%PL)** | | | | 0.7970 | | |
| 0-200 v >400 | | | 1.07 (0.87 - 1.32) | | | |
| 201-400 v >400 | | | 1.01 (0.84 - 1.21) | | | |

| | | | | | | |
|---|---|---|---|---|---|---|
| **Education** | | | 0.3365 | | | |
| No HS v college | 1.11 | (0.80 - 1.55) | | | | |
| HS grad v some college | 1.16 | (0.95 – 1.43) | | | | |
| **Family Structure** | | | 0.0202 | | | 0.0151 |
| 2 parent v Other | 1.00 | (0.74 – 1.36) | | 1.02 | (0.77 - 1.35) | |
| Single parent v other | 0.79 | (0.58 – 1.08) | | 0.81 | (0.60 – 1.07) | |
| **Breathing Difficulty** | | | <.0001 | | | <.0001 |
| a lot v none | 0.37 | (0.27 - 0.51) | | 0.33 | (0.25 - 0.44) | |
| a little v none | 0.85 | (0.64 -1.12) | | 0.77 | (0.59 - 1.00) | |

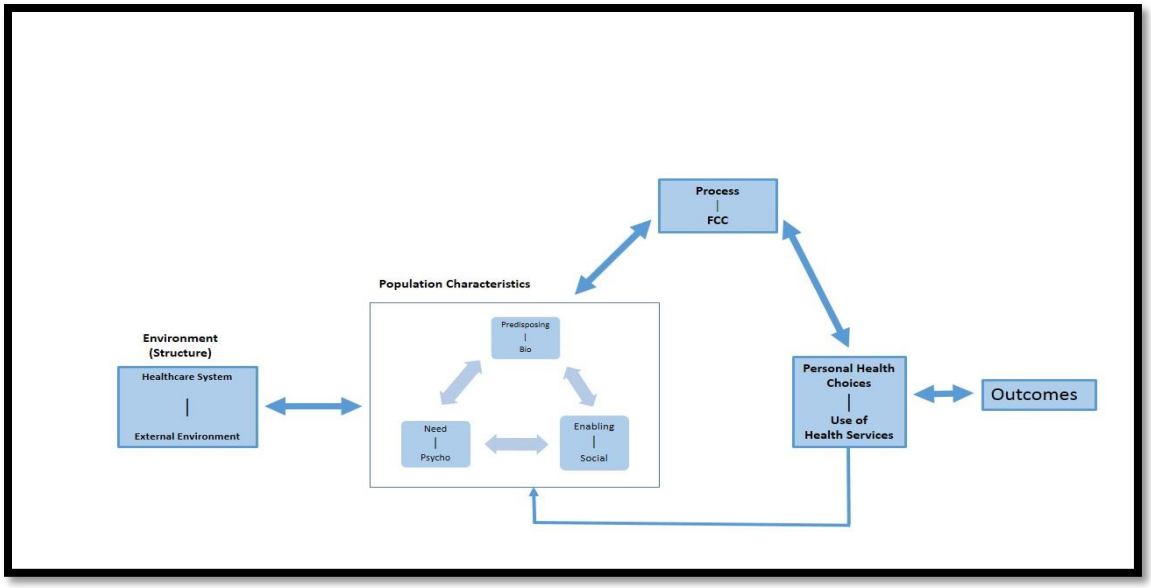


**Figure 5.1 Conceptual Model**

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